PM(hel)L

Losing a Loved One to HIV
Alec's Journey

Lylo de Lange

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In Loving Memory of my best friend and life partner, Alec Willem de Lange, who was tragically taken by this disease on 25 April 2008. Alec, there was nothing I would not do for you. If we could swap places, I gladly would. You were, and still are, my everything.

And my father, Lourens Daniël Stols, who passed away during the course – and partly as a result – of Alec's illness on12 April 2008.

And Heidi Lindner who passed away on 16 February 2012, who in the process of helping me became one of my closest friends and confidantes.

n. blog

A weblog.
intr.v., blogged, blog·ging, blogs.
To write entries in, add material to, or maintain a weblog.
[(WE)BLOG.]
web·log (wb'lôg', -lg')
n.
A website that displays in chronological order the postings by one or more individuals and usually has links to comments on specific postings.

www.answers.com

Acknowledgements

A wealth of people stood behind me in the compilation of this journal. Invariably, names will be left out, mainly because one does not keep lists of people who offer you a friendly word of advice. To those – I really appreciate your advice and help.

I do however wish to single out one group of people and a few individuals: The blogging community of News24.com who, day by day, stood by Alec and me; offering words of encouragement, a silent prayer and invaluable support.

To Mark Davies and Sue de Bruyn, thank you for assisting me in making this journal see the light, and your unfaltering belief and trust in me.

Lastly to Dexter and Tayron – thank you, from both Alec and myself, for your love and understanding. You have picked me up a thousand times over. I will always be indebted to you.

Preface

13 January 2009

Yet another day, another morning has broken. Daylight streams into my room – the new room I occupy nowadays, Dad's old room – the master bedroom, the room he and Mom used to share when I was a boy. Now they're gone, both of them.

Heidi is in the next room, my old room. No, my and Alec's old room. Sleeping, still. Of course, Alec moved with me to my new room, or at least, his ashes did.

I wonder what the day will hold for Heidi and me. For the past few days things have not been going well between the two of us, we've been rather snappy and at each others' throats most of the time. I'm the one to blame, I know – with my continuous threats of suicide. My continuous drinking. It's been wearing her down.

"Good morning," says Heidi wearily behind me in the kitchen. "Good morning" is my forced and strained reply, before retreating back into my room with my mug of coffee. At least we didn't snap at each other.

Heidi starts with her normal Tuesday chores. Today it involves doing washing, without a washing machine. She offers to do mine, I decline. I'm still too bitter, too upset about the words we had the previous night. I tell her I will do my own washing, and continue reading my book – *The Lighthouse* by PD James – a new author she introduced me to. Every so often, I stare out of the window, looking out on the lawn that is now overgrown. The thought crosses my mind that Dad would be disappointed in me. But what can I do? As I'm staring out onto the garden, I can see Alec and me planting the *Cyrtanthusses* under the lemon tree. I see family braais under the trees. Alec wandering through the garden, looking for a flower to pick for me, an offering next to my bed, as he so loved to do. I see Dad on his knees, planting out his broccoli and cauliflower seedlings, carefully giving each plant a scoop of water after the transplant. And I begin to cry, again. Nothing new.

I have deteriorated. Badly. I am in the grip of a severe depression, where every day has become a fight between "live" or "die". A situation where I wake up each morning, sort of grateful that I have survived yet another night, yet more significantly disappointed that I am not dead; grieving for not one, but the two people I cared for most. Yet another day where I have to try and find a blade of grass to cling on to, where I hope to find meaning in loss and in death. A day where I *must* try to find something to live for again – a reason to go on.

I gather Heidi is done with her washing – I no longer hear her in the bathroom. I strip the linen off my bed and start emptying my washing basket. At the bottom of the basket I see the orange bag I have noticed so many times before. It's been there since Alec moved in with me in June 2007. He put it there. Perhaps there's some money in the bag that we can use, maybe we can buy some smokes. I pick it up and feel it; it does have some weight to it, not heavy, but there is something in there. I recall the day we moved Alec's belongings to my house. "What is in the orange bag, Alec?" I asked. Alec replied "just another bag and some stuff, nothing important".

Nearly nine months after his death I open the bag and look inside. Just another brown shoulder bag, like he said – but the weight I was feeling is now in the shoulder bag. I open the bag and peek inside – a book, an envelope with photos. I select the envelope first and pull out the photos. "Heidi!!" I exclaim, choking in tears. Heidi rushes into the room, worry carved into her face, replaced by disappointment to see me crying uncontrollably – again. "What's wrong?" she asks and I point to the pile of photo's, on top of which lies a photo of Alec, in life, smiling, happy, exuding life itself. "Oh my soul, I haven't seen these before, where did you find them?" Between tears I explain to her about the orange bag. We rummage through the photos, looking for clues, answers. I cry. A weary Heidi tries to comfort me. I pick up the book – *AIDSafari* by Adam Levin.

More questions: Did Alec know he was HIV positive? Did he know Adam? Why this book specifically? Why now?

Some more discoveries – the envelope containing the photos has a name written on it – Ellno, in Alec's handwriting. I recall an e-mail I received somewhere in July 2008. The name of the person who sent the email escapes me, but the content of it does not. The email read something like: "We were sorry to read about your loss on your blog. We are devastated as well. The person you knew as Alec was known to us as Ellno. He must have changed his name when he moved up to Johannesburg from here in Cape Town. Did he still paint when he was with you? He was very artistic. Did he at least go peacefully?" Inside the envelope are photos of paintings – I can't be certain Alec painted them; I can but only make the assumption he did.

In July 2008, after Alec's death, I started to write a journal about my journey with Alec, after he contracted Progressive Multifocal Leukoencephalitis, or PML for short. A disease I did not know about. A disease that, I dare say, 90% of South Africans do not know about. A disease I wish I had never encountered. A disease I wish no-one to encounter. But I never got around to finding a publisher for the journal.

After Alec's passing, I approached Wits University with an offer of medicine that was imported into South Africa illegally, in a bid to try and save Alec. I wanted them to do research on it for potential use in PML cases. When I spoke to the head of their HIV Research Initiative the person said to me that it was the first time she heard of PML. She declined the offer of the medicine for two reasons – it was imported illegally (understandably), but also because "there were far more important opportunistic HIV infections, such as TB", to warrant any research into something rare like PML.

I did countless searches on the internet for ongoing research into either the JC Virus (the virus that causes PML) or PML in South Africa and none came up. Not at university level, nor on the Medical Research Council's website.

On the website belonging to the Treatment Action Campaign, I came across a document entitled *Treatment Action Campaign's Guidelines to Opportunistic Infections Associated with HIV/Aids* – PML wasn't even mentioned! I entered into correspondence with them – begging them to inform their members about PML and explained the frightening statistics. They replied thanking me for my time and promised they would insert PML into their list of opportunistic infections. To date nothing has happened – almost a year down the line.

To me it felt as if nobody cared about PML. No-one was interested.

And so I too lost interest – in everything.

I sat on my bed with the book I had found in the bag – *AIDSafari*. I read Adam Levin's handwritten words on the dustcover: "I'd read about Aids in the papers and had some idea of the crusade to manage it, but despite being gay, 30 years old and resident of the country with the highest AIDS rates in the world, I was completely ignorant about the realities of this disease. Like so many of us, I was a victim of the secrecy surrounding it."

The impact of these few sentences did not escape me – it gave new meaning to my own journal, my journey through hell with PML. Unanswered e-mails. Closed doors. Inaction.

And so I decided – you *have the right* to know.
I can no longer sit with this toxic silence. It is eating away at me, like an insidious pathogen.

PM(hel)L is a journal in two parts. The first gives some background to my relationship with Alec and how we met. The second consists of my blogposts from 18 February 2007 to 29 April 2007. The blogposts are mostly unedited, with only obvious spelling mistakes corrected, to keep them as authentic as possible.

Because I wanted to protect Alec's HIV status I did not blog about the true cause of his illness. Therefore I have added notes to my blogposts, notes which contain my thoughts and memories and those feelings I could not blog about at the time. Also contained in Part Two is correspondence that took place between myself and other parties, who assisted me greatly with Alec's illness. These are also left unedited except for obvious spelling mistakes.

It has not been possible to copy in all the comments received on every blogpost I posted, as the support from the blogging community – strangers all, was overwhelming.

The blog posts are all copied from my blog called Jessy's Jungle (*http://mynewsblogs.24.com/jessysjungle*), where I discontinued posting on 06 May 2008.

Other blogs you might want to visit are:
Daddy A (*http://mynewsblogs.24.com/daddya*) (News24.com keeps this blog as an online memory of Alec's life)
Interesting Life (*http://mynewsblogs.24.com/interestinglife*) (Heidi Lindner's blog)
In Memory (*http://blogs.24.com/inmemory*) (A blog that was created by a fellow blogger as a Memory Kit upon Alec's passing)

PART I – Alec and Pieter

15 June 2007 to 17 February 2008

“What should I put down as an answer to this question here?” asked my sister, Joey, that Friday night. Since her divorce in February we had rediscovered our kinship and shared common ground. We were busy working on one of her Unisa assignments, one dealing with Business Management, where she had to do an analysis on a business and determine its health and future.

“Huh? Sorry, I missed that one”, I replied rather absent-mindedly. Whilst Joey had been busy typing on her own laptop, I was checking out my profile on Gaydar, and had just received a new message. It read: “I find you incredibly attractive. I dare you to contact me. Guythings”. I replied something to the effect of: “Thanks for your message – you ought to have your eyes tested. I am not attractive and besides, my profile says – no photo, no chat”. I added a smiley face or two so that my reply did not sound too harsh, because somehow I liked this guy’s initiative.

“What are you busy with – you’re supposed to help me with my assignment, not whore around on the net. It has to be in on Monday and last time I checked it is now Friday night”, Joey grumbled.

“Just a guy on Gaydar saying I am attractive. Probably won’t answer again because there is no photo of him”. As I finished saying that, I saw a new message arrive in my inbox and clicked to open it. “Give me your MSN address and I will forward my photo to you. You won’t be disappointed”. And “Guythings” gave me his MSN address as “security”. I added him as a contact on my own list and within seconds we were chatting. He forwarded me some photos of himself, and I was immediately struck by how handsome he was. In between helping Joey with her assignment I discovered that Guythings had a name – Alec – and that he stayed on his own in Potchefstroom, a city some 45 kilometres from where I lived.

That weekend we chatted on and off most of the time and found we had a lot in common. We both felt that we wanted to get to know each other better and because of some link to a website that I had sent him during the weekend, his laptop contracted a computer virus. I therefore undertook to drive through to Potchefstroom on Monday the 18th and take some of my own software to remove the virus.

I arrived at his flat, a studio apartment in an upmarket block of flats with primarily students as occupants. The moment I laid eyes on Alec, I was struck by his physical beauty. I can recall feeling that there was no way someone as attractive as Alec would be interested in someone like me. Our forced introductions were awkward at first, but Alec's offer of a glass of Rosé and my desire to rid his laptop of the virus soon gave way to an amicable conversation.

It was while I was loading the Antivirus software onto his laptop that a call came through on Alec's cell phone. It was obviously someone checking in on Alec to see if he was okay and to establish that I was not an axe-murderer or a serial rapist! I was obviously none of the above and after ending the conversation, Alec called me to his lounge window and said I should look up into the sky. His friend, Annemarie, wanted us to look at something in the sky. He had his hand on my shoulder as we stood at the window, and besides feeling that his hand was strong, I could also feel a quiver – excitement perhaps? We stared in amazement at a sight not many people get to see in their lifetime – the Occultation of Venus with the Moon. While experiencing this phenomenon we both realised, without any words being spoken, that we had found each other, and that there would be no-one else for us.

We sat down in his lounge and he placed a CD in his player – Buddha Bar IV. As the soulful music of *Le Fille de Pekin* by Frederic Rousseau filled the lounge I asked Alec what emotion it evoked in him and his reply was that of love and togetherness. My reply to his similarly phrased question was that there was definitely romance in the tune, but also a sense of loss and tragedy.

It was after midnight when I left his apartment. We did not have sex on our first date; for me it was unimportant, we had found each other and there would be plenty time for that!

For the next few days we chatted each free moment we had on MSN, sending each other little endearing messages of love, of encouragement. On Wednesday the 20th he asked me if I would like to join him for his birthday the following day, and I said, without any hesitation, that I'd be delighted.

I was living with my elderly father and his lady friend, Martie, an elderly lady. I had converted an outside room into an office in order to run my business from home, which allowed me to be close at hand should the two elderly people need me. Having the office outside meant that I could lock the door and separate my work-life from home-life at the end of the day.

Whenever something of importance needed to be discussed between the three of us, I would arrange a meeting in my office, and a house meeting was called on Thursday morning, 21 June 2007. Both were anxious to hear what I wanted to talk about, and I recall that I was crying with excitement when I broke the news to them – "Dad, Martie, I've met the man I want to spend the rest of my life with. It is his birthday today and he has invited me to his birthday party tonight. I have decided to go, and I will, in all probability, not return home until the morning." I continued to give them some background about Alec and explained that I wanted to invite him over for the weekend, so that they could all get to know each other and for them to see if they would get along with Alec, as it was my intention to invite him to come and live with us. Dad was his cautious self, but noted that he had seen a change in my general mood since the Monday, and that it was in order for Alec to visit us for the weekend. Martie was equally excited, and both of them wished me well.

Thursday evening could not arrive soon enough and I stole away earlier from home than our agreed time. Upon arrival at Alec's apartment, he told me that the party could begin, seeing that all the guests he had invited were there. I was the only one present, and it took me a couple of seconds to realise exactly what he had said – he wanted no-one else at his birthday party but me!

Up until that day I had not believed in love at first sight. For me it was a silly romantic notion – something that belonged in Mills and Boon paperbacks. I was proved horribly wrong. I had the option to either take Alec out for dinner or we could order some pizza and enjoy it at his apartment instead. We both decided on the pizza, as it would allow us more private time together and enable us to get to know each other in a more intimate setting. We set off to Roman's to order our pizzas, and *en route* stopped off at a bottle store to buy some wine. At the local Spar I saw a bunch of orange roses which appealed to me and I spontaneously bought them too, with some Ferrero Rocher chocolates. At his apartment, Alec took me in his arms and gave me a huge kiss, thanking me for the roses – his favourite. I told Alec that the roses were a small token to mark his birthday, and that he would have to wait a while to enjoy his larger present, a weekend away at Victoria Falls in September.

We did not eat the pizza that night and it was with a very heavy heart that we parted the following morning, with the promise that we would see each other again over the weekend.

Alec did not own a car, so I drove through to Potchefstroom to fetch him from his workplace on Saturday the 23rd. After picking up his overnight bag from his apartment, we drove through to visit Pieter and Jay Jay, friends of mine who owned a coffee shop in Klerksdorp – they wanted to meet this beau who had completely swept me off my feet. At this very early stage we jokingly referred to a wedding in March, and Jay Jay quipped that perhaps we should plan a double wedding. The mood was jovial and Alec was immediately liked by them.

We set off for home, as it was time to introduce Alec to Dad and Martie. There was no stiffness in the introduction and Dad went out of his way to make Alec feel at home. I noticed something else – in the past I had always had great difficulty introducing new, potential partners to my Dad. With Alec it was quite the opposite – holding hands and showing affection for each other came quite naturally, and neither Dad nor Martie seemed to take any offence. Another surprising thing that happened that day was that out of his own accord Alec started calling my father Dad!

I intended impressing Alec with my cooking skills that day and planned to make a lasagne for supper, but after I asked him what he would prefer, and learning that he loved to braai, I changed my plans, and a braai it was!

On the Sunday Alec helped me prepare lunch and while we were seated at the table Dad invited Alec to move in with us. I was surprised, but at the same time elated, that the two of them had established rapport so quickly and easily.

We made arrangements with a friend of mine who lived in Stilfontein but worked in Potchefstroom that Alec could get a lift through with him and his colleague daily and contribute towards their petrol expenses.

On Thursday 28 June, I took half a day off from my own business, to go and collect Alec from work to take him to the Department of Home Affairs to apply for his new passport, as his old one had expired. We also decided that after the ordeal at Home Affairs, we would go to our local Clinic in Stilfontein to have HIV tests done, because we wanted to be sure we were both safe. We arrived at the clinic only to find that of all the afternoons, that was their afternoon to be closed. Both Alec and I were a bit anxious about going for the test; in my younger days I had been quite promiscuous and indiscriminate about sex, while Alec had ended a relationship because he was expected to participate in threesomes and foursomes and it went against his grain. We regarded the clinic being closed as a sign – a blessing if you like – upon our relationship. I recall saying: "You know what Alec – I fell in love with you! Not your HIV status. Whether you are HIV+ or HIV- it will not change how I feel about you. Perhaps the clinic being closed is a sign for us that it is not necessary to have the test done." Alec replied that he felt exactly the same way. We both convinced each other that we were healthy and that it was completely unnecessary to go for the test.

Both of us disclosed that – to the best of our knowledge – we were HIV–. We were so ignorant in our thinking that if either of us were HIV+, it would surely have shown by then. And so we drove away from the clinic, undertaking never to think about or act upon it again.

Alec and I settled into a very comfortable domestic routine. The lift club worked out perfectly. I am an early riser, so in the morning I would get up at about 05:00 or 05:30, go through to my office and catch up on that important thing that is put aside when the phones start ringing – admin. At 06:00 I would go through to the kitchen, make coffee for us both and then go to wake Alec. We'd lie in each other's arms and watch breakfast telly till it was time for Alec to get up to have his shower. I'd go back through to the office again for another half hour or so, and then make Alec's second cup of coffee at about 07:00. Between 07:15 and 07:20 his lift club would pick him up and then I would go and have my shower and then go through to my office to start my working day properly. By the time I arrived in my office Alec would already have sent me an "I Love You" message on MSN.

At about 16:00 I would start preparing dinner and I would expect Alec to be home any time from 17:15 onwards. Dad was always sitting in the lounge, so as Alec walked into the door I would hear the exchange: "Hi Dad, how was your day?". "Hi Alec, fine and yours?" "Fine thanks Dad". Then he would come through to the kitchen, and we would give each other a big hug and a kiss, before he went to the room to put his laptop down and change into more comfortable clothes. By the time he got back to the kitchen, I would have poured him and Dad a sundowner and we would sit down and relax before having dinner.

Tradition in our house was that Dad would say grace for the food we were about to eat and then after dinner I would say a thank you prayer for the food we had just eaten. Somehow it just felt a bit presumptuous to say grace for the food I had prepared myself. On about the third or fourth evening that Alec was with us, he asked: "Dad, would you mind if I say grace tonight?" To which Dad replied that he would be delighted if Alec did. That night Dad moved the responsibility for saying grace over to Alec. When Joey came through for lunch the second Sunday that Alec was here, my Dad turned to her and said: "I hope you don't mind, but I have given my youngest son the responsibility for saying grace." My heart nearly burst with pride at that point – Dad publicly acknowledged Alec as his youngest son!

Being a hair stylist, Alec had to work on Saturdays and his lift club was not available over weekends. Initially, I took him through to Potchefstroom every Saturday, but after a while we decided that he could afford to only work every second Saturday. Our trips to Potchefstroom were always very special to me: Alec would sit next to me in the car, with his hand on my upper leg, lighting us each a cigarette, chatting. Opposite the salon he used to work was a coffee shop called Burgundy's. I used to have a table reserved for me on the Saturdays Alec worked – right at the back, out of the traffic, yet with a perfect view of all arrivals and departures. Most times, a friend of Alec's, Annemarie, would join me from about 10:00 and we would just sit and chat, sipping on a glass of wine, perhaps having breakfast. On the times when she did not, I would sit at my table, blogging. Every so often, Alec would sneak away between clients and come and sit and have a cigarette with me. The coffee shop owner (also Pieter) and I soon became friends. He and Alec were friends already and he was also one of Alec's clients. Often he would sit down with me, enjoying a cup of coffee and chatting about matters of the day. On other days I would sit and read the newspaper, whilst I waited for Alec to finish his 08:00-13:00 shift. From where I sat I could see the salon and when I saw Alec was approaching the coffee shop with his bag over his shoulder, I would order a Windhoek Draught to be at the table ready for when Alec sat down. I remember one particular Saturday, one of he first one's there, that I had a slip of the tongue and said to Pieter "Please would you bring me a Windhoek Draught for my husband?" He looked at me with huge eyes, which soon gave way to understanding and since that day we jokingly referred to Alec as "The Husband".

After the Windhoek Draught, and perhaps a second one, Alec and I would decide what we wanted to do the rest of the day. Very early in our relationship Alec insisted that I not be responsible for cooking on Saturdays as well. He explained, of his own accord, to the rest of my household that as I was cooking every day of the week, he felt that on Saturdays everyone had to fend for themselves. So we would decide where we would have lunch – at Burgundy's, at another restaurant, or perhaps just a braai at Annemarie's house.

Everybody in my circle of friends accepted Alec as my better half. Nobody asked questions, when people saw us together, it was automatically assumed that we belonged together.

In August I started blogging on *www.24.com*, writing under the name JessysJungle, named after my Jack Russel bitch. I wanted my blog to capture life as seen through the eyes of a Jack Russel. Jessy had a few characters in her life: Daddy P, which was me, Daddy A

(Alec), Grandpa (my dad), Grandma (Martie – as dogs cannot distinguish between whether people are married or not and in Jessy's eyes, Martie was her grandma) and Aunty Fag Hag (a lady friend of mine, Ina, incidentally Martie's sister in law). Jessy looked at matters political or topical with her own set of preconceptions: if you can't eat it, or bark at it, you piss on it. At more or less the same time, and in quite another part of South Africa, a lady, Heidil, started blogging under the pen name "Interesting Life". JessysJungle and Interesting Life very soon started a blog friendship – both authors had a strong stance against abuse of women and children as common ground. It was not long before Heidi and I started emailing each other – exchanging ideas, offering opinions, forming a friendship.

Alec started blogging in September. Great was my surprise when I received a comment on my blog from a certain Daddy A – the name Alec chose for his blog. I did not know that he was going to take up blogging! And so it was that the three of us started an internet friendship – Alec, Heidi and I.

In September we got an addition to our household. Ina, Martie's sister in law, invited Alec and me along for a weekend at her daughter's house in Rustenburg. As it was, at the time I was experiencing problems with Martie in regards to her abuse/misuse of medication, and I needed to discuss a possible course of action with her son. When we arrived at their house, I noticed that they had acquired a new dog, a Jack Russel male, but Roelie, Martie's son, helped me right telling me that it was a stray dog that had arrived there out of his own accord. They called the dog Milo, and Alec and Milo formed an immediate bond – Milo would jump onto Alec's lap as we sat outside, something the dog had never done in the week since he had arrived, according to Roelie. On the Saturday Roelie informed us he would probably have to take the dog to the SPCA as he did not have the space for a third dog. Alec burst into tears and looked at me in despair: "Please can we keep him, Pieter?" How could I say no? I never could say no to Alec when he cried. On Sunday Milo went home with us to Stilfontein – Alec now had his own Jack Russel.

I always tried to take Dad away for a holiday once a year. Earlier in 2007, March to be exact, we had a 10 day family break in Ramsgate after Joey's divorce came through. While in Ramsgate, Dad mentioned his desire to see Victoria Falls again before he died. Since Dad had given us all a fright in January 2007, by falling ill on New Years Day, I decided in May to start planning a weekend away at Victoria Falls. I chose the weekend of 21 September and started setting everything in motion. At the time, it would have been Dad, Martie, Joey, her daughter Adele and I who would have gone. In the meantime I had met Alec, and so I asked him to join us for the weekend as his birthday present. As it turned out, Joey and Adele could not join us due to work commitments on Joey's side.

The four of us set off for the airport very early on the Thursday morning. Alec was as excited as a child. He had only been to Botswana before and that was by car. It would be his first flight on a Boeing. We were at the airport early and made our way to an airport lounge, where we had to have coffee, as it was not 10:00 yet and they only start serving alcoholic beverages at 10:00 at that particular lounge. As soon as the clock struck 10:00, Alec ordered Windhoek Draught for the two of us, much to Martie's disgust. She had been grumpy since we left home that morning.

Alec was trigger happy with the digital camera and took photos of almost anything he could lay his eyes on. I remember feeling heartsore at the time – it was such an inspiring experience to see someone so excited about something others take for granted. Our flight was exciting and Alec was mesmerised about flying through the clouds. I was in the clouds myself – the man I loved with all my heart was sitting next to me and we were about to embark on some very exciting activities together during the course of the weekend.

The weekend for me was half business and half pleasure, while for Alec, Dad and Martie it was pure pleasure. Upon arrival at Livingstone Airport, we were met by a representative of the company I used for my Zambia bookings who was to transfer us to our accommodation. I remember Zambia being very dry and brown at the time, as we had arrived just ahead of the rainy season – but that made game viewing easy. On the road leading to the lodge we were to stay at, we encountered two elephant, and Alec was over the moon. Our driver was kind enough to stop and allowed us to watch the elephant as they grazed the Mopane scrub. As if on cue, a fish eagle let out its soulful cry, and I knew then we were truly in Africa, and Alec and I would make memories here. We drove the last 100 meters to our lodge, content with the elephant we saw, and checked in.

The lodge is situated on a tributary of the Zambezi River, and after checking in Alec, Dad and I went on to inspect the grounds and to familiarize ourselves with our environment. We ended up at the bar, which had a wooden deck extending over the Maramba River, and I ordered us my standard drink when in a malaria area – gin and tonic. I recall being surprised that the Zambian people were able to speak Chichewa, a language from the neighbouring Malawi, and I recall the waiter being surprised at me using the language. Dad sat smugly on his chair; I could see he was proud of his son addressing someone in a language they knew. Alec was mesmerised and immediately set to task to learn the greetings, at least. It was a splendid afternoon, just the three of us. The mood was to change, however, later that evening, when I lost my cool with Martie because she complained yet again about trivialities. For me, it felt she expected the whole world to revolve around her and her comfort and that she disregarded everyone else. Alec dined, against his wishes, with Dad and Martie, and told me later in our room that he had reprimanded her for being selfish and demanding. I was proud that Alec had stood up for me.

We had a hectic day ahead of us on the Saturday. Part of the reason for us going to Victoria Falls, was for me to familiarise myself with the situation on the Zimbabwean side of the Falls, and as such, a prospective ground handler arranged for me to visit six hotels on the Zimbabwean side the following day. Alec and I decided some time earlier that we would also like to mix in some pleasure at the same time, by making a bungee jump, taking a helicopter flip ("Flight of Angels") and enjoying a sunset cruise whilst in Zimbabwe for the day. We woke up very early the Saturday morning and nothing was said at the breakfast table about the altercation I had had with Martie the previous night. Alec and I said our goodbyes and left Dad and Martie to their own devices for the day, whilst setting off for our first adventure – the bungee jump.

I recall telling Alec that if he did not want to do the jump, it would be okay by me. To be honest, I do suffer from a fear of heights, and I was rather hoping Alec would chicken out. Alec's reply came loud and clear: "I am scared, but I want to do the jump with you. I want to do it for you." I had no chance of chickening out! We arrived at the jumping station after weighing ourselves in on the mainland. The long walk to the middle of the bridge took place in silence. Alec indicated that he wanted to jump first, and the operators ensured that they had the correct jumping cord on for him. After preparing Alec for the jump and taking him through the safety procedures, Alec jumped, shouting "Pieter, I'm doing this for you!!!" I had a lump in my throat. They started preparing me for my jump and I remember being concerned about how Alec would get back onto the bridge. I didn't realise that there was a walkway below the bridge on to which jumpers were hoisted, and the "jumpmaster" took time to explain to me how they worked. As I was ready to jump, they had just hoisted Alec onto the bottom platform and the jumpmaster, knowing it was Alec's first jump, shouted to Alec "Alec, how was it?" From where I stood, ready to jump, I could neither see nor hear Alec and his reply was lost to me. My jump was exquisite and the adrenalin rush was amazing, and all too soon I found myself on the disembarking platform. Upon enquiring about Alec's whereabouts, the operator there told me that Alec was already off the bridge. He led me along the walkway to where he had left Alec and I could see immediately that Alec was crying. I thought that perhaps the jump had scared him and that he was suffering from shock, but Alec immediately put my mind at ease, explaining that he was crying because he was grateful for the opportunity he had been given to jump, but more importantly, the operator had not allowed him to wait for me to be hoisted up. He wanted to be waiting for me went I got back onto the bridge. Being in Zimbabwe, Alec and I were very wary of showing any signs of affection towards each other. I so much wanted to hold him in my arms and hug him and kiss him, but I could not, out of fear of persecution.

The rest of the day was spent inspecting hotels. I was escorted around to the various venues by a representative of the prospective ground handler, a lovely lady by the name of Chenai, as well as the hotel managers of each of the venues. Alec trailed behind or wandered off in his own direction, taking photographs of everything he deemed important for me to use in my business.

After we had inspected three of the hotels, it was time for our 15 minute helicopter flip over the Zambezi and the Victoria Falls. Both of us were awed into silence and quiet respect. Following the helicopter flip we inspected three more hotels before going on our final adventure of the day, the sunset cruise.

It was a leisurely cruise along Long Island, in the Zambezi River, on the Zimbabwean side. Some people call it a booze cruise, and not without good reason: a waiter will appear at your table, and ask you what you would like to drink, and then serve your drink to you, and as soon as this drink is almost finished, the next one arrives! We were sitting on the upper deck, with Chenai, when Alec recognised one of his clients. There were also some of the spectators from our jump on the cruise. They offered to take photos of Alec and me and we decided to drop our guard, threw caution to the wind and were ourselves. We held hands, had our arms around each other's shoulders, pointed to hippos in the Zambezi, remarked about a wedding taking place on an island in the Zambezi, and it must have been there that we formalised our decision to get married as well.

The Sunday was our last full day in Zambia, and with the business part of our trip being over for me, I planned to spoil my Dad and Martie that day. We took a walk-about on the Zambian side of the falls. When I was 7 years old, my Dad took us to the former Rhodesia and we visited the Falls during that trip. I can remember that we saw the familiar bridge spanning the divide between Zimbabwe and Zambia, but we could not cross it, because of terrorist activities and the fact that Zimbabwe and Zambia were at war at the time. Now, finally, Dad had the privilege to see the falls from the Zambian side. Alec was bounding around like a child, surprised by each angle he saw the Falls from. From one vantage point we looked at the bridge from which we had bungeed the previous day, and neither of us could believe we actually did the jump, despite watching the DVDs we got from the jump a number of times.

We returned to the lodge for lunch and a rest before we embarked on a final sunset cruise, this time with Dad and Martie, on the Zambian side aboard the African Queen, a beautiful barge. It was on this cruise, and after Alec had to assist Martie to go to the ladies room on the lower deck, that I noticed a change in Alec's behaviour. He became withdrawn, and kept to himself. I thought that perhaps he had had too much to drink. It was only later that night after dinner, while he and I were sitting on the deck overlooking the Maramba River, that I found out what had caused his change in demeanour. On the way to the ladies" room, Martie had told Alec that she could not understand what Alec saw in me. And that remark hurt him a lot. He was also heartsore that we were leaving the following day and wished that we could stay a few days longer – without Martie. Alec opened up to me that night and told me about his childhood, how he had grown up with his grandparents, because his own mother and stepfather (he did not know his biological father) were too busy to look after him. He cried about how good it felt to be part of a family again, he cried out of frustration about Martie's general ungratefulness. We spoke a lot that night. I explained to Alec that I was grooming him for a position in my business, and that I planned an educational trip to Zimbabwe for February 2008, whereby a select few travel agents would accompany us to familiarise themselves with the Falls, and that he would go along as a shareholder in my business. I also suggested that we would do a lunar bungee jump (the operator in Zimbabwe offers bungee jumps when it is full moon – with the mist rising from the falls, it creates a rainbow around the moon and it is reputed to be a sight to behold). We also talked about passing away that night, and what our wishes were. It was agreed that whoever remained behind would scatter the other one's ashes at the spot where we sat and looked at the bridge from which we had bungeed. It was not an intentional discussion – it just happened, naturally.

The following day we returned to South Africa – our little sojourn in Zambia ingrained in our memories, forever. We left Zambia, an Alec and a Pieter who were much much closer than before.

Life continued as normal after our return. We blogged, Alec went to work in Potchefstroom, I worked in my little office. A familiar domestic routine. Though we had spoken of marriage, I had not formally asked Alec if he would marry me. I knew that he was the man I wanted to spend the rest of my life with. I knew he was the man I wanted to grow old with. Prior to knowing Alec, I had always maintained that I did not want to grow old. I regarded 60 as the perfect age to go. After meeting Alec, that point of view changed. I wanted to grow old with him, even if it was 80 years, or 90.

On the 18th of October I got a bee in my bonnet to do an online marriage proposal to Alec, knowing full well he read my blogposts daily. This is what I posted on that day:

18 June 2007 – Occultation of Venus with the Moon

8:29AM, Thursday, 18 Oct, 2007

Hi there

P here. Jess and Milo are busy re-arranging the rose bed.

I feel it is time to shed some light on the 18th of June and how Daddy P and Daddy A met. Champagne, yep, we met each other on the internet just like you and your better half. And so curious was I, that I took the big step on Monday, 18 June 2007, to meet A in person. Unbeknownst to him and unbeknownst to me, the lunar system played along and gave us an occurrence of great significance on the astrology cards.

Whilst sorting out a virus problem on A's computer, he received an SMS which instructed him to look outside at Venus and the Moon.

And that is when we just knew we were meant for each other. Both of us were awed by this phenomenal sight. Since that night, the longest we have been apart, was two nights.

A, today is our 4 month celebration. And I just want to say thanks for being part of my life for 4 glorious months. I know, as you, that the next 4 will be just as great.

Thanks for crossing my t's. Thanks for dotting my i's. Thanks for bringing some sanity in to my otherwise insane world. Thanks for being patient with me and most of all, thanks for allowing me to be me. You really do bring out the best in me. And I could not have asked for a better life partner.

A. We have discussed it. Made assumptions and informal decisions about it. Even got ourselves around to arranging it. Got informally engaged. However, I yet have to ask, and I now ask you formally, for everyone to see!!!

Will you marry me?

Love
P

All our blog friends waited with bated breath for Alec's answer, which finally came in a comment left on my blog:

Daddy A
Ja, ja, ja, ja ek sal, daai oomblik bly in my hart, was ongelooflik, my sprokie bewaarheid ... Dankie my engel ...
Posted 2007/10/18 09:32:20 AM

Translated: Yes, yes, yes, yes I will, that moment stays in my heart, was unbelievable, my fairytale came true ... Thanks my angel ...

A couple of minutes later Alec posted the following on his blog:

Die vraag is gevra, wow

9:49AM, Thursday, 18 Oct, 2007

Trou met jou

Sal jy met my trou, yinne gedink ek droom ... My hart klop in my keel & voel 'n bietjie lam ... My hele hart sê ja ja ja ja ja ja , verstaan nou die liedjie "my hart goes bang" so goed. Goeiste die trouplanne sal natuurlik deur my beste vriendin Sus A gedoen word ... Ek is so sprakeloos, wow. Gaan wonderlik wees. Gay en gaan nou trou, ek is gevra. Voel so gelukkig.

Dankie

Jy maak my lewe vol liefde en kleur ...

Daddy P

Translated:
The question has been asked, wow

Get married to you

Will you marry me, geez, I thought I was dreaming ... My heart is beating in my throat & I feel a little dizzy ... My whole heart says yes yes yes yes yes yes, understand that song "my heart goes bang" so well now. Goodness the wedding arrangements wil naturally be taken care of by my good friend, Sis A ... I am so speechless, wow.. its going to be wonderful. Gay and now getting married, I have been asked. Feeling so happy.

Thank you

You fill my life with love and colour ...

Daddy P

So after asking the big question and on the Saturdays that Alec had to work, Annemarie and I would sit in Burgundy's, planning our wedding. We knew that we did not want something big, rather a smaller and more intimate ceremony and reception. Annemarie and I decided that the three of us take a drive one Sunday to view a prospective venue, a lapa in one of the closeby nature reserves, called Faan Meintjies. The venue suited Alec and I perfectly and we could already picture exactly how the ceremony would proceed, what we would wear, what we would have for our guests to eat. We decided to get married in court on the Friday, and then have a Blessing ceremony on the Saturday. Alec, Annemarie, Simone (Annemarie's daughter) and I, then enjoyed a braai at a braaispot close by, further discussing décor and matters related to our special day. We planned a late afternoon wedding, with the ceremony taking place as the sun set. After our braai we went to Pieter and Jay Jay's coffee shop for a last drink and to share our good news with them.

December arrived all too soon.

Since my mom had passed away about 20 years ago, as a general rule, Dad and I never bothered much with Christmas decorations. Alec was insistent, however, that he wanted a Christmas tree, because, as he put it, he had never enjoyed a proper Christmas with a family. As we were now his family, he felt that we should do the whole Christmas decoration and tree thing. We had a slight problem though – Martie had lost one eye to glaucoma a few years previously, and any light, especially flickering lights and candles, affected her other good eye severely. We solved this little problem by making our room a Christmas Haven. We set off to buy a small tree and decorations and lights. I let Alec decorate the tree, since he had never had the privilege to do so.

Christmas lunch, on the other hand, has always been a huge affair in our house. Dad and I would commence with the planning of the Christmas menus in October. Since I had discovered how to roast the perfect turkey, and since Dad discovered what turkey should taste like, that was always a given on our Christmas menu. This year, I went a bit overboard with the lunch menu, since it would be the first time in nearly 25 years that my Dad would have both his children to share the day with him. And it would be the first Christmas in 13 years that I would not be single. So in addition to the turkey, there would be leg of lamb done in a Greek style, and ox tongue. I also planned an array of salads and desserts. Traditionally I did all my food preparation and the cooking on the 24th so that come the 25th, I had nothing else to do other than slicing the meats and making a green salad.

I was married to a beautiful woman called Santa, many moons ago. About a year into our marriage I finally realised and accepted that I was gay, and Santa and I tried to live around this fact for another five years before we got divorced in 1995, and despite the divorce have remained good friends. Santa was in town to visit her family over the festive season, and phoned to find out if I perhaps wanted to go out for a quick beer with her. I was dying to introduce Alec to Santa, and after popping the turkey into the oven, we set off to the local nursery, which also has a coffee shop. Alec and Santa took a liking to each other immediately and they chatted as if they had known each other for years. It made me feel happy. After two beers it was time to go home and check on the turkey in the oven, and Santa came along to visit with my Dad for a short while. She made his day by calling him Dad, just as I still call her parents Mom and Dad when we see each other.

On Christmas Eve Joey joined us for our traditional evening braai. After we had eaten, Joey, Alec and I set off to look at the different Christmas light displays in the gardens around Stilfontein. One house in particular had an unusually beautiful display, and for the first time since they started their light display a few years back, had opened their garden to the public, so one could wander in and look at all the lights from every conceivable angle. I remember Alec pinching me a red rose from their garden that night.

Christmas Day was filled with much joy and happiness. Not only did Dad have his daughter home, but also his two granddaughters and their boyfriends. We had Christmas crackers and party hats, and the conversation was light, easy and jovial. After lunch the granddaughters and their boyfriends left and Joey, Alec, Dad and I retreated to our room as Joey wanted to show us the photos of her holiday she had spent with her youngest daughter a few weeks earlier. I carried my office chair into the room for my Dad to sit on, while Joey, Alec and I made ourselves comfortable on our bed. We had a great time viewing the more than 1200 photographs on our TV via the laptop.

Christmas over and Old Year's Eve followed, and we invited Annemarie to share the evening and New Years Day with us, along with Joey. On the spur of the moment early in the afternoon of the 31st I suggested a burial ceremony. This was done mainly for Joey's benefit, as she was battling to come to terms with her divorce earlier in the year. My intention was that each of us at the party select a rock, give the rock the name of our biggest worry of the year and then bury it – by digging the rock's "grave", holding a burial sermon, mourning the "death" of the rock, and we would be in effect laying the worries of 2007 to rest. At the time all but Martie thought it was a good idea, and all in all I still feel it was a good thing to do. People looking at us must have thought we were a bit odd, but it was done for the betterment of Joey primarily. Afterwards we had our braai and again after eating, Joey, Annemarie, Alec and I set off to go and look at the Christmas light displays. And again, Alec pinched me a rose!

New Year's Day was spent lazily – eating, drinking, being merry. It was during our lunch that I recalled how my Dad had given us all a fright in 2007 by falling ill on New Year's Day. I remember, as I proposed the toast to 2008, how Dad said that he still had a lot of life in him for at least the next ten years! All of us were set for a fantastic year and Alec and I informed my Dad and Martie about our pending wedding in March. We had set the date for March 15.

Life pretty much continued as normal. Towards the end of January Alec went to see a doctor about a skin condition he was developing, and the doctor placed him on a strong antibiotic. All of a sudden, Alec started stuttering inexplicably. And then the stuttering disappeared again. This kept recurring, and on the 8th of February I took Alec to my own doctor. He asked what medication Alec was taking and we gave him the name of the antibiotic, upon which he inferred it might be a temporary side-effect of the medication. He suggested we be patient and that it would take about two weeks for the medication to work through Alec's system before things would return to normal.

There was no improvement. While the stuttering was not debilitating, Alec still continued to work, and communication was not a problem at all. But then there was another change that started to set in. Alec liked to help me in the kitchen while I was cooking. I noticed that Alec would give me different things from what I had asked for. For instance, I would ask for a plate, and Alec would hand me a saucer. Or I would ask for a spoon, and Alec would give me a fork. This too, I ascribed to the “side effects” of the antibiotics.

Which it wasn’t.

PART II – The Journal

Monday, 18 February 2008

No blogpost was done on this day regarding Alec's condition, I merely add this date as it is the day everything started officially.

Alec was dropped off at home by a member of his lift club at 17:00. She informed me that Alec had had a stroke at work. I led Alec into the house and all he could do was indicate that he could not talk. It did appear stroke-like but there were other signs that it was not a stroke. I phoned my house doctor and he asked that I bring Alec through to his house so that he could check him out.

The house doctor ruled out a stroke and suggested that there is some other neurological problem and that it would be imperative for Alec to have a C/T scan (Computed Tomography). As instructed I kept Alec quiet that night. He slept peacefully, yet I lay awake for most of the night.

Message from HeidiL

9:47AM, Tuesday, 19 Feb, 2008

Hello everyone

With Pieter's permission i have blogjacked his blog.

Daddy A is having a brain scan today and we are all very worried about him.

I want to appeal to all of you to send your thoughts, well wishes and positive energies in the direction of Quiet Fountain today.

I have personally been the witness of the power of positive thoughts and i know that by your upholding this very special family in your prayers, the outcome will be a positive one.

To Pieter and Daddy A i want to send my own special thoughts to you today – i am thinking of you and i know everything will be okay. You both have come to mean a lot to me in a short space of time! You are both very special people.

Pieter, you are an inspiration to us all. Stay strong – and know that you have the support of all your blogfriends.

Lots of love from Down by the Sea

Heidi

Notes: I phoned Heidi on the 18th of February to tell her what had happened to Alec. Having no experience with the Public Health System, I firmly believed that Alec would have his C/T scan that day.

Because Alec had to be at Tshepong hospital very early on the Tuesday morning, I asked if Heidi would be prepared to post on my blog on my behalf, which she agreed to do.

At this stage Alec and I still hid behind anonymity. It was upon compiling this journal that I realised Heidi had unknowingly and unintentionally made my name known to the blogging community. Whenever I wrote about the town I lived in, I referred to it as Quiet Fountain, a literal translation of Stilfontein.

Feedback – from P himself

2:49 PM, Tuesday, 19 Feb, 2008

Hi All.

Heidi thanks very much for the blogjacking and keeping our blog friends up to date. You are such a special friend.

Now, the story. Some two weeks ago I blogged about Daddy A possibly suffering side effects from an antibiotic he had taken a week or two earlier. In this time Daddy A has started stuttering – he does not stutter normally. This has deteriorated to where yesterday I became quite anxious because he cannot speak, and one of his work colleagues mistook it for a mild stroke. All I know is that at 17:00 his lift club dropped him off, dumping all of this on me. A was very incoherent and very confused and I immediately rushed him through to my house doctor. The house doctor ordered a brain scan, *but* because neither of us are on medical aid we have to utilise the services of our famous Dr Manto.

I took A to the hospital this morning, opened up an account for him and thus began the wait ... Eventually we got to see a Dr. M (a Polish doctor). Very friendly chap and all, and I feel comfortable that A is not with a horse doctor – if you catch my drift. They have now done every imaginable blood test you can think of, and his CAT Scan is scheduled for Monday. The scan depends on some of the blood tests, *plus* the hospital we were at provide CAT Scans for the entire North West Province (or so they say), so you can't just walk in and have a scan done – you have to make an appointment.

In the meantime the doctor said he must rest a lot and he will only decide on Monday what course of action he is going to take. A is very frustrated, because he can understand what you say to him, he just can not get around to verbalising his thoughts. Just to get a simple "yes" or "no" out of him, sometimes take ages. At other times, it happens normally and one wouldn't say there is a problem.

The GP reckons we should rule out a brain tumour, hence the scan, because of the speed at which this thing has set in.

So – thank you for all your wonderful comments on Heidi's earlier post, but I wish to *beg* of you to keep A in your thoughts. I am clawing at the edges of a very dark depression as I feel so utterly helpless, but I know I have to be strong now, for his sake and mine.

I shall keep you posted on A's progress. And he did ask me to say thanks for your comments of support on the previous post. I will try and do his normal C/P on his blog, but probably will only get around to it tomorrow – at 02:00 I was still wide awake and at 05:00 I was up and about already, so I desperately need some proper rest so that I can get out of this on setting depro.

You take care, and again, thanks.

P

Notes: The wait at the hospital was very long that day. Tshepong is one of the provincial hospitals. What did annoy me was the fact that the doctor did not want to acknowledge my presence with Alec in his consulting rooms.

Now for you to understand this I need to give some background: Alec and I had plans to get married on the 15th of March 2008. Although we were not married, as far as I was concerned, it made me his legal partner. And therefore I had every right to be there. The doctor did eventually relent and allowed me to be present during the consultation.

Making an appointment for the C/T scan also annoyed me that day. I can recall that I told the nurse who controlled the appointment book that we do not know whether Alec is dying or not. Her reply to me was that Alec was healthy and that people do not die that easily. It was no comfort to me at all, but Alec tried to calm me down and we left it at that.

Wednesday morning update

6:58 AM, Wednesday, 20 Feb, 2008

Morning all

Amazing what a good night's rest can do to restore one's senses. I'll be honest – I was very despondent yesterday. I hate to see A in this condition as it makes me feel so helpless, also being at the hospital for nearly a full day just to have "nothing" done, is also very frustrating. Monday night was the worst for me. Such a lot of thoughts went through my brain. All those nagging "what if" scenarios. What would I do without him, why must it happen to us, what have I done wrong, is he going to be okay, what is wrong with him, is he on drugs and I don't know about it, is he going to die? Then, when I wanted to sleep, the moment I put my head down on my pillow, I hear this music, strange music, and the moment I take my head up again, the music is gone. So it was that sometimes after 02:00 (I remember the 2 because I watched a National Geographic program), I must have fallen asleep finally sitting upright in bed. Only to wake up just before 05:00.

However – this morning I feel much much better and I realise that a hell of a lot of work lies ahead now. And I am not going to take it lying down – that's for sure.

Yesterday morning in the car, on our way to the hospital, I told A that no matter what, I will always be there for him and that we will get through this together. I regard this as our 7 bags of proverbial salt. On our way back I phoned Dad to tell him that I am dropping A off at home and will then go to Spar. A indicated to me that he also wanted to go to Spar. And that's when I realised that he would not want to be treated like an invalid. So dinner time I told Dad and GF that the way they can help is to not expect any answers from A. They can talk to him, since he understands perfectly well what you say to him, but he only finds it difficult to speak. Sometimes it comes easily, but usually it doesn't happen. So at the moment our conversations basically consist of *yes* and *no*, and only sometimes a little bit more, but not long complicated sentences.

A has also restored his sense of time and presence. On Monday he did not know which day of the week it was and where in SA we were. He knew he stayed in Quiet Fountain, yes, but he could not place it in a province. He thought it was in the Cape. Also he thought it was Saturday. Now I am happy to report that he indeed remembers the day of the week and the province, and I regularly do little tests to establish his senses. Yes, sometimes he becomes frustrated by it, but I have to know his condition if I want to help him, I have to pick up any signs of deterioration or improvement. Small steps at a time.

Once again we say thanks for your thoughts and prayers. I don't think you will ever realise what they mean to us.
Wishing you a wonderful fabulous day.
Love
P
PS: Rose, again thanks for your email. It was exactly what I needed at the time!

Notes: During my visit to my house doctor on the Monday I noted that he had asked Alec simple questions like: "What is your name?" "Where do you stay?" "What day of the week is it?" etcetera. From that day on, I repeated those questions to Alec, in a bid to assist his doctors, in order to keep checking whether there was any deterioration or not. I also explained to Dad and Martie (GF) that they must not be too demanding on Alec and expect elaborate answers. For Alec it was very frustrating because once he had been able to speak properly and now had aphasia.

I had a good nights rest on the Tuesday night and I felt a bit perkier. Shortly after posting the above, I received a phone call on Alec's phone. It was from the doctor's rooms that Alec had been taken to on the Monday – they wanted to see us urgently. So I posted the following:

Interesting

9:13AM, Wednesday, 20 Feb, 2008

Hi there

I did mention in a previous post (yesterday) that A went to see a doctor on Monday when they thought he might have had a mild stroke. During this visit they took blood tests. A could not remember which doctor he went to and attempts from my side to find out whom proved unsuccessful. They phoned this morning on his phone and they need to see him today still. The results of those tests are now available.

Both of us are now very anxious, understandably, but we will be there at 11:30 to see the doctor. This will mean one step closer to finding out what is wrong. Please think of us.

I think this is it from me for this morning. Will give some feedback this afternoon.

Care

P

Notes: I remember that I could feel the anxiety in the pit of my stomach after receiving that phone call. The receptionist said that it was imperative we get through to them on that same day. She suggested 11:30. It sounded so ominous and after about 10 minutes of worrying about it, I picked up the phone and called the doctor's rooms and asked if we could not perhaps come through sooner. The lady was very friendly and said that we could come through immediately and she would fit us in between the other patients.

Alec and I left immediately for the doctors, who were in Potchefstroom, some 45 kilometres from Stilfontein. Alec was quite anxious about going, as the doctor's rooms were right across from where he worked. He did not want his colleagues to see him, for fear that they would think he is playing truant. So I parked on the opposite side of the doctor's rooms so that they could not see my car, and this helped Alec to feel less tense.

I remember on the drive there that the thought did cross my mind – "what if it is HIV?" But it couldn't be, I assured myself, as Alec was healthy – more healthy than what I was at the stage.

We were shown through to the doctor's room within 5 minutes after arriving. I remember him to be a very handsome man. His name was Emile. Emile K. As he sat down, I explained who I was and why I was there, and he gave me the impression that he was happy for me to be there with Alec.

Then he looked Alec straight in the eye and said: "Sorry mate, I have some bad news for you. You are HIV+."

Alec burst into tears, and at the same time a certain calmness came over me and I just took him in my arms and hugged him. I told him that it did not matter to me. That I did not fall in love with him because of his HIV status. I fell in love with him as a person.

The doctor then proceeded to ask if I knew my status and I said no. He recommended that I go for a test as soon as possible.

Emile explained why he wanted to see us so urgently. He suspected that Alec might have an opportunistic HIV related infection, and if we could catch it in time, he might be cured. But in order to do that, Alec needed a lumbar puncture urgently. Neither of us was on a medical aid, and, he explained to us, if we were going to follow the private route, we would pay dearly.

He suggested I take Alec back to the doctors that saw him the previous day in Tshepong. He also recommended that I take him straight through to Casualty, because of his potentially life-threatening condition.

Emile asked if we were Christian and we nodded yes, to which he asked if we minded if he said a prayer for us. Till today that prayer means such a lot to me.

Alec and I left for Tshepong immediately. In the car I reassured him again that we were in this together and that I would stick with him – No Matter What. I did however tell him that we would have to inform Dad and Martie about his condition, but that they are the only people who needed to know. I would not reveal it on the blogs or to his work colleagues. Alec understood and seemed at peace with it.

We arrived at Tshepong and I took him through to Casualty, where they duly informed me that Alec could not be seen immediately, and he needed to follow the day-patient route. We went through to the sister in charge of the day-patient section, a woman I had admired up to that point, and explained to her what had happened. She was kind enough to take us through to the same doctor who had seen Alec the previous day.

However, the whole situation was misunderstood by this doctor. He thought Alec and I had gone to see another (private) doctor behind his back and that we did not trust him. The sister in charge told me that Alec was in this condition because he had known he was HIV+ and had neglected to tell me about it, and therefore got anxious about it now that it had caught up with him. She suggested that perhaps Alec should see a psychologist to help him to get over the shock. I lost all my respect for her that day.

The psychologist could not see Alec before the C/T scan ruled out a neurological problem. And the doctor refused to do a lumbar puncture, because he said that it could be life threatening. What did happen, however, was that they drew a blood sample to determine Alec's CD4 count and viral load on my insistence. This was against the doctor's wishes, though, because he said Alec looked far too healthy to have a low CD4 count, and to perform CD4 counts unnecessarily is costly..

I did the following update shortly after our visit.

Wednesday update

3:35 pm, Wednesday, 20 Feb, 2008

Hi all

I am emotionally drained at the moment, after a hectic day of doctors, and even a psychologist.

We could not wait until 11:30 as we felt as if a death sentence was being issued, so I called the doctor to see if we could see him sooner. He said we could come through immediately and so we rushed out of here by about quarter to 10. Got there and he explained why A needed a lumbar puncture to test for the one or other fungal infection – but he can't do it, we have to do it at the provincial hospital.

We then rushed to the hospital. The doctor said that we should go to Casualty. Arrive at Casualty, no they say, we have to follow the clinic route. Went to the sister in charge; thankfully she was Afrikaans and very understanding and rushed us through all the procedures. The doctor who saw us yesterday saw us again today, and thankfully the results for the tests we did yesterday were available. He explained why he was not going to (do) a lumbar puncture – there is a very easy easy test to see if it was needed. If A could not bend his neck forward, it would have been necessary, as the fungal infection is always associated with meningitis. All his other blood works are okay, only a slightly higher cholesterol result than normal. So it is now only that we have to wait until Monday for the cat or C/T Scan. Everything points to a neurological thing since its onset is so quick. We were referred to a psychologist who listened to everything and said that we will have to wait till Monday when the results for the C/T Scan are available.

Although the first doctor gave us a huge fright stating that A had to have a lumbar puncture today, we are feeling better now that the second doctor has explained to us why it is not necessary. I work on evidence and am probably a doctor's worst nightmare, and he gave me the necessary evidence.

So though today was sort of a wild goose chase, we could rule out three possibilities already, and as I say, everything now points to a neurological problem. The doctor also requested a new set of blood tests, whose results we will have on Monday.

Other than that – I am exhausted and taking the rest of the afternoon off. Thanks for your kind thoughts. Have a fabulous evening!!

Care

P (& A)

Notes: You'll note that nothing was said about HIV in the blog, because I wanted to protect Alec.

We arrived home after our visit to the hospital: I poured each of us a stiff whiskey and sat Dad and Martie down in the lounge with us. I held Alec's hand and in a very trembling voice I told them what the doctor's had said and informed them that Alec was HIV+.

I explained the difference between being HIV+ and having Aids, saying that Alec can still live till he is 80 and actually die of natural causes, as long as we keep him on anti-retrovirals. Dad said that he would never reject Alec for being HIV+ and Martie seconded that. We cried with relief, and I undertook to have my HIV test done the following day.

Thursday morning feedback

8:16 AM, Thursday, 21 Feb, 2008

Hi All

Happy to report that both of us had a good nights rest. Today I have plenty of work to catch up with – the past two days have taken its toll on the office. A is fine at the moment. He can still remember which day of the week it is, he still knows in which province we are. So I take that as a good sign. Also, sometimes he doesn't struggle with his speech at all. However that is only sometimes, not all of the time.

I have to be honest that I am suffering a major depression, if I could call it that. Maybe I am just temporarily down. I struggle to keep my composure in front of A, and I know this is not helping either of us. But perhaps I'll be giving it the middle finger because I know we *will* get through this. We *will*.

Thank you all once again for all your comments of support, for your concern, for the emails we get and even suggestions as to what to check for. We really appreciate that and it is hugely comforting.

Have a terrific Thursday all. I'll report back a little bit later.

Take Care

P

Notes: What I did not mention in this blog was that I was extremely anxious, because I had to go and have my own HIV test done at our local clinic.

Alec and I went there straight after posting this. Because we already knew his status, it was not necessary for him to undergo the test, but I could see that he was anxious about what my result would be.

After the normal obligatory and meaningless counselling session, they proceeded to prick my finger to get blood to do the test. It came back negative. I felt so disappointed at the time. How lonely Alec must have felt?

I was advised to return in three months to have another test done. Apparently there is a three month window period in which the virus shows itself. And since we had only found out recently that Alec was HIV+, and because we had had unprotected sex, I had to go back in three months time for a follow-up test. We were also given a packet of condoms, because Alec and I used to have unprotected sex. Dad and Martie were happy to hear that I was not infected with the virus.

I did myself a favour ...

12:52PM, Thursday, 21 Feb, 2008

Hi all

I realised that I am not going to get through this on my own. So I went to the doctor this morning and explained all my fears. I am very inquisitive and with all the givens we have at the moment one knows what to look for and what can be ruled out. And one of my discoveries, which fit the symptoms, is the possibility of a brain tumour. Okay, some of the symptoms are not present, but one that is ever present is aphasia, the inability to speak. According to my doctor there is a 40% chance that A might have that. If so, it will be disastrous news. And when I mean disastrous, I mean worst case scenario and very quickly. I must commend my doctor. He was very emphatic, heard me out and said to me that he will support me all the way.

That left there – I am now on a tranquiliser that I will have to take daily. He gave me one immediately and then from tonight I must take one tablet for at least the next 30 days. I feel a bit more in control. When we got back home, A and I sat opposite each other and I held his hands in mine and apologised to him for cracking up. I told him that I plan to have him around for at least the next 40 years. But the only way we can achieve this is if both of us are positive and remain so. I will be there for him, every single step of the way.

What we are going through at the moment is horrendous. I can't even begin to explain how awful it is. Which makes me think – do we really appreciate our loved ones as we should? Do we really do what we must do every day? Don't we sometimes take our better halves for granted?

Yes, I am unsure, and I am petrified because of my own bloody inquisitiveness – and Google. But boy, if that brain scan comes back negative on Monday, I think I'll down a whole case of champagne.

In the meantime, it is this bloody waiting that is getting me under, but luckily with the happy pills, that will keep me in control and in check with A.

You take care. Will check in later

P

Notes: I used Google to research some of Alec's symptoms. His aphasia and HIV+ result made me think that is was possible that Alec might have a brain tumour. If he had a tumour, there was nothing the doctors would be able to do for him. Prognosis would have been 2 years maximum.

This had me very upset and I decided to go and see the doctor. I decided not to share the information with Alec because I did not want to upset him. Alec and I went through to see my house doctor, but I asked Alec to stay in the waiting room while I was in with the doctor.

Dr H is a very patient man, he listened to me and then chastised me just a little bit for taking the Google route. He said that I must remember that a computer has no compassion and cannot impart bad news with a human touch. What one reads on the internet are stark, cold facts and that it was unwise of me to have done so. He did however tell me that I should feel free to contact him at any time, with anything that I needed to discuss; he then prescribed a mild tranquiliser to help me cope.

Last update for Thursday

4:28PM, Thursday, 21 Feb, 2008

Hi there all

The happy pills are already starting to work – *Hallelujah*. I am very anti-medicine (*sic*), but in this one instance, I realise I do need it. And I am happy to report that I am much much more positive. Which means I can be much more supportive of A. He said to me this afternoon it upsets him when he sees me cry, and I can feel with the meds, I have no need to cry. I can think about things positively and not negatively. And I have to be positive, because God knows, A needs it.

I have also discovered that I have a wealth of friends here in blog land. Heidi, Lyndatjie, thanks for your calls of support. MissTiGGeRr, Blanket, Rose, you have revealed your cellular numbers for me to use should I need them. Thank you for that. Then all of you that send all your positive energy this way around – *Thank You, Thank You, Thank You*. It is so nice to know that we are not alone.

And I promise to stop googling now. Why worry about worst case scenarios when probably all it is, is a viral infection of sorts that have the same (*sic*) symptoms.

Love you all, BUT please do me ONE favour. After reading this, go to your loved one and tell them you love them. And make it a habit. Every day, 50 times a day. But don't only say it – *mean* it.

Take care
P

Notes: After a failed suicide attempt in 2004 involving anti-depressants, I am very anti medicine. But I realised that should I want to help Alec to overcome what he had, I would need to lean on some kind of a crutch. I also realised on this day that life is indeed short, and that one should appreciate your loved ones. Not that I did not appreciate Alec, I just felt on this day that there had to be more I could do.

The night of the 21st would also be the last night that Alec and I had sex, and perhaps in order to make myself feel better that I was HIV- rather than HIV+, I decided to show Alec my unconditional love for him and had unprotected sex with him. As I told him – "we are in this thing together".

The fact that it was our last night of love making was unintentional though. It just happened that way, and in hindsight, it was great.

It was also the day that I discovered you cannot love your loved ones enough, Alec being ill made me feel helpless, as I wanted to take that illness away, make him better, take it on me.

Friday morning

8:58AM, Friday, 22 Feb, 2008

Good morning All
Once again *thank you* for your comments of support, phone calls and emails. It really means a lot to us and I do read each one to A.

Happy to report that both of us had a good night's rest. A appears to be more positive this morning, as well as having all his senses. I gave him loads of questions to answer and he had them all right. For now it seems as if it is only the speech that is affected.

I'd rather not say how I cope emotionally, all I can say is that it is very difficult at times. It feels like a roller coaster – up the one moment and down the next. If he looks into my eyes for clues or answers my heart feels like bursting and I feel like cracking up.

Though A has maintained his weight so far, I have lost 2kg since Sunday. I weighed Jessy on Sunday to establish her weight, and did so again this morning, so I picked up my weight loss that way.

Both of us thoroughly enjoyed watching *Strictly Come Dancing* last night. *Wow*, the competition is stiff, really, but Emmanuel and his partner were deserving winners. My money is on them to win this competition.

Now tell me. Have you held your loved one's face in your hands and given him or her a kiss and told them you love them today? Just wondering….

Have a good Friday

Love

P

Notes: I always used to read Alec the comments of support that our fellow bloggers had left on our blogs. Alec always enjoyed them thoroughly and the comments made him smile. A smile that melted my heart.

What happened of significance on this day was that shortly after this post, Alec and I took the Bible and he gave his heart to God again. Alec was always religious, but because of his upbringing, he became a bit rebellious in the religion department – Alec's parents had rejected him because he was gay, and he had not seen them in over 20 years. I took his hands in mine that morning, and I asked him if he would perhaps want to give his heart to God again – reconfirm his loyalty to God, so to speak. Alec said yes.

I read several passages from the Bible to him that morning, but the most important one I read him were John 3:16. I explained to him what the verse meant – that it was an all-inclusive verse, pertaining to everyone. I explained that the verse pertains to anyone – not just people who go to church, but ***anyone*** who believes in Him, whether that person is gay or straight, a murderer or an adulterer – his/her sins have been forgiven by just believing. He had tears in his eyes and then we prayed – it was as if he tried to pray with me. That is how I know that he had truly given his heart to God – the fact that he tried to pray along.

Emotionally it was an extremely difficult time for me. I had constant feelings that I was about to lose Alec, despite the tranquilisers I was using. I'd be up the one moment, down the very next. As far as possible I tried my best not to show my emotions to Alec. As a result of being so concerned about Alec, I could not eat, I felt extremely nauseous when eating, resulting in a loss of weight on my part.

A poem, for Alec

10:47AM, Friday, 22 Feb, 2008

Hi there

Just thought I'd pop this poem in for Alec. He won't read it today, I know, but perhaps, soon, he will read it. But it is how I feel. Now, and forever.

Always and forever

Basking in the warmth of your smile
And the music of your laugh
I feel your tenderness
And your oh so witty style

I don't know why God blessed me
With such a friend as you
But it makes my pleasure complete

And very happy too

The way you always know me
And exactly what to do
When my loneliness gets me down
And I'm so very blue
The way you see into my soul
And looked behind my eyes
And I don't have to hide my feelings
And put on a disguise

With you I learned to trust
And as I person I have grown
Who could have possibly told me
How could I have known
That you would come in to my life
And my beauty would start to bloom
And like a pretty butterfly
Come out of my cocoon

To share your tender heart
The warmness of your smile
The courage of your wisdom
For these I'd walk for miles

To be thinking of a time
When you'd no longer be there
For me to gaze upon in delight
And all our feelings share
Is not acceptable to me
Because in my life
Is where I want you to be
Always and forever.

Notes: Shortly after our re-commitment ceremony with God, I posted this poem for Alec. I decided to drop our anonymity and not hide behind the names Daddy A and Daddy P (or A and P) any more.

I don't know who wrote this poem, it was something someone sent me in an email, but that was how I felt that day and I wanted to share it with him.

Friday afternoon update

2:25PM, Friday, 22 Feb, 2008

Heya

Have sent the man to bed for a bit so that he can rest and I can cry without him seeing me.

I said that I do cognitive tests every day to see how in control he is with his senses. Like asking him in which province you would find Durban, etc., etc., etc. It is important that I do this, so that we can spot any deterioration immediately.

What I have not done the whole week was to ask him to write something. So this morning, and with his spirits up immensely, I wrote on a piece of paper:

"Please write me a little letter about anything that pops up in your mind – take as long as you wish, try your best."

I did this specifically so that I could see whether he understands what is expected from him.

So he started writing. What I see there are the scribblings of someone who has just started to write. He gave up after 2 minutes of trying, bursting into tears of *utter* frustration because he can't write.

Guys, I am so devastated for him. I am so hurt for him. I am *sooooo* scared I'm going to lose him. I try my best to remain positive, I try my best to be strong, but my heart aches soooo much for Alec. And I feel so utterly helpless.

Please forgive me for dumping on you – but you are all I have to dump on.

Will try and post again a little bit later.

Take care

And oh yes – tell your loved ones you love them. And mean it. Please.

Pieter

Notes: Alec was very distressed because he could not write anything. He tried so hard, I know, and I was upset with myself because I felt I was putting too much pressure on him. And he was frustrated because he must have felt he let me down.

Every afternoon Alec went and slept a bit in our room. During the morning, he sat with me in my office, and then when he was ready for his nap, he would go to our room and sleep a bit. I used this time to get rid of my tears, frustrations and angst.

I needed to talk to someone that particular afternoon and I decided to slip out of the house a bit and go and spend some time with a lady friend of mine. We always confided in each other about our problems.

She confided in me that afternoon that her one son was experiencing marital problems and I confided in her that Alec was diagnosed HIV+. We both promised each other that what we shared would remain strictly confidential. I learned a couple of days later that she had breached our confidentiality. I felt that I had betrayed Alec.

Saturday Morning

10:47AM, Saturday, 23 Feb, 2008

Hi there all

Much, much, much more positive this side. Both Alec and I had a good night’s rest. Alec even brought me coffee in bed this morning.

I felt at one stage last night I could not cope anymore and I phoned Heidi and had myself a long and good crying session whilst Alec was in the room watching TV. I felt much better. Thanks so much, Heidi.

Heidi also gave me some tips on what I can do. Our aim is to keep Alec as positive as possible and there was a window of opportunity yesterday when I posted on his blog. I did not know his password, and he could not say it to me *but* he could type it in for me. So today, we are going to see how he is doing with typing. Here's to holding thumbs.

After my crying session with Heidi, I went back to the room and felt a lot more at ease. Which enabled me to speak calmly to Alec. It appears as if he had an anxiety attack at work. See, the stuttering started about three weeks ago, but it was not as debilitating as it became on Monday. When I asked him if someone was rude to him at work he nodded yes. What happened is that one of his clients was impatient with him because Alec stuttered when he answered him. He told Alec that he was rude. Now Alec is very embarrassed about this stuttering problem he has, and I can only imagine that he must have suffered an anxiety attack. This anxiety attack I think, was mistaken for a mild stroke (that's what his colleagues told me). Now on his way to the doctor, which is just opposite his place of work, Alec saw a hit and run accident. And, I suspect, the shock of seeing this happening right in front of his eyes compounded the anxiety attack he had already suffered in the shop.

So I think, and I hope I am right, *yes*, there is an underlying problem which has caused the stuttering to set on BUT something aggravated it on Monday, and *that* thing I suspect (and I am no doctor, don't get me wrong) is severe shock.

Alec is much calmer this morning. He can give more comprehensive sentences albeit still short. He is much more positive. And he is much more patient with himself. And for me, I am much more positive too. I will not lose any hope – I can't, because I want to spend the rest of my natural life with this man, and I will do my damnedest to support him. I am not going to allow him to go and sit and mope about this. And he is looking forward to seeing Anne and Simmi this afternoon, who are popping over to visit him.

Again – guys, girls, friends, strangers you may be in that we have not met in real life, but your constant prayers, thoughts and comments have already had an amazing effect on Alec (and me). And for that we will be forever indebted to you. Thank you, thank you, thank you.

PS: Checked on his laptop now that he is working on, how he is progressing. He typed: "Ai, ek wil net vir jou se ek is lief vir jou", which translated means "I just want to tell you I love you" Now *that* is immensely positive, don't you think?

Take care. And remember (and you will hear this often from me now) tell your loved ones you love them. And mean it. You can never do it enough. Don't let it become rhetoric. Mean it every time you say it!

Take care

Pieter

Notes: I was elated when Alec typed that into his laptop – “I just wanted to tell you that I love you”. It meant so much to me. He found the visit from Annemarie and Simone very uplifting. Annemarie was like a sister to Alec. I remember when they arrived, Annemarie took Alec in her arms and just hugged him.

Our friendship with Annemarie was a very solid one. And we had this standing rule that whenever we visited one another, we would have a meal together – nothing fancy, just a meal. I decided to make a lasagne for that day because it was a dish Alec enjoyed immensely. And we had a good bottle of wine.

We decided to share Alec's status with Annemarie and Simone – it was for the best. And it was nice to see and feel their support.

In hindsight though, and after months of reading up on PML and the course it takes, I realise that Alec did not suffer an anxiety attack. He merely nodded yes and no to questions I had asked him. He did utter the word accident, but whether or not he had actually seen an accident, I would never know, because I had to make assumptions as to what he meant. I take it he did, because he was able to type that sentence into the laptop and it was logical and comprehending.

Sunday update

9:42AM, Sunday, 24 Feb, 2008

Hi there all

We are awed beyond compare. I just visited a few blogs yesterday and most of them I visited have some message for Alec and myself. *Thank You, Thank You, Thank You.*

Anne and Simmi were here yesterday and Alec thoroughly enjoyed their visit. Alec and I made one of his favourite dishes, lasagne, and it was thoroughly enjoyed by all. Thanks Anne and Simmi. Both of us have had a good night's rest. Thank you Lord for that. Today, however, is going to be a bummer I think. Alec keeps on asking me questions I can't and won't answer. And he is frustrated beyond compare. We just hold each other a lot and keep telling each other that we love each other. I think it is the waiting for the C/T Scan tomorrow that is wearing us down a bit. And silently in my heart I pray that God would rather take this sickness away from Alec and give it to me so that he can stop worrying.

I will probably not be doing a post tomorrow morning as we want to leave for hospital very early so that we can get this test over and done with. But I will try my best to do a post later today – in the meantime, I want to spend as much as possible time with Alec and I want to spend as much as possible time praying for healing.

On the upside – he still has all his cognitives in place. He still remembers his name, he still remembers where Cape Town is, and when he answers questions it is with much more vigour than yesterday. So I do pray that this is a good sign. What is getting me down is that a 37 year-old man went from nothing wrong to a virtual grown up baby (I mean this in the nicest possible way), in less than a week. And *that* is scary to us both.

Again – thanks for your prayers, your thoughts, your emails, your phone calls, your comments. I do not think that you will *ever* realise what it means to both of us. *Thank You*.

God Bless

Pieter

Notes: Sunday did not start too well for us: Alec was full of questions – I think he knew that I knew something and did not want to share it with him. I tried hard to avoid the questions. Questions such as WHAT is wrong with him? WHEN is he going to be better? WILL he get better? And I decided not to tell him what I feared, PURELY because I am not a doctor and certain tests needed to be done before we could find the answers. I can but only imagine how distressing it must have been for him.

I tried to pacify him by just holding him, constantly re-assuring him of my love, telling him that everything was going to be okay. Both of us had our own set of uncertainties about what was going to transpire the following day at Tshepong Hospital. The waiting and waiting and questions without answers were getting to us both. I don't think anyone could blame us.

My pledge

5:21PM, Sunday, 24 Feb, 2008

Hi All

You do not want to read my original post. I'll spare you from it for now. In the meantime – all maintain the status quo. Will report back only tomorrow afternoon. Please keep us in your prayers.

Love
Pieter

Notes: The day progressed from bad to worse, with Alec being very tearful and frustrated. It hurt me immensely to see him like that, and being powerless to help him. I think for the first time the harsh reality that I might lose him set in.

So... I made a pledge in a blog post to Alec. I wanted him to know that he was not in this alone, that he would not die alone. That I would be by his side and with him when he died, should he die. And that I would take my own life. But I decided to remove the pledge before it was read, out of fear for unwanted and negative criticism from my fellow bloggers. I think we were both so unsure as to what was going to happen the next day.

Message from heidil

8:12AM, Monday, 25 Feb, 2008

Hello everyone

As you all know A is having the CAT Scan today. Please continue supporting him and Pieter in your prayers and positive thoughts today!

I spoke with Pieter last night and they are both positive and up beat about the results of the Scan and they wanted me to thank you all from the bottoms of their hearts for all the support – via email, phone calls, smses and comments, as well as many thanks to all of those people who placed special thoughts and prayers for them on their own blogs! They are completely overwhelmed by the support and just want you all to know how much you have come to mean to them.

Please fellow bloggers, keep sending your positive energies their way. I am sure that the result of the CAT Scan will be favourable, as A has made good progress over the weekend.

A and Pieter – you are being carried on the wings of prayer today. May all your Guardian Angels surround you with their love, comfort and hope.

Lots and lots of love and very big hugs from

Heidi

Notes: Heidi became someone I could rely on. With Alec sometimes being demanding due to his condition, there was not always time to blog. I did try to blog as often as I could, but sometimes it was just impossible. I had to run a household of 4 people, I had to run a business, I had to look after Alec. So often-times, if I wanted to get an update out I would let Heidi know how things went.

On this particular day we went to Tshepong very early again to avoid long queues ahead of us. In the end they could not find Alec's file and we waited very long before they finally found it. So much so for the early bird that catches the worm.

People are strange creatures. Strangers. I remember sitting in the queues and people staring at Alec and me. Some would even ask outright what the matter was. And then I would put on my complacent face and say that they suspect a form of encephalitis – a non-committal answer.

Update by heidil

1:52PM, Monday, 25 Feb, 2008

Hello everyone!

Pieter has just phoned me to tell me the good news! The CAT Scan shows no sign of a tumour!

Alec is now in hospital where they are running a number of other tests, and he also had a lumbar puncture this afternoon.

The test results should be back later today or tomorrow morning so then they will be able to start treating Alec and setting him on the road to recovery!

They have both asked me to say a huge **THANK YOU** to all of you for your thoughts, your messages and for your prayers! Thank you to those people who have been setting up prayer chains across the country – if anything today has been indicative of the power of prayer, and of how positive thoughts in the right direction can make a difference!

Pieter has said he may post in person later tonight, or only tomorrow, but if he is unable to, then i will continue to keep you all informed and up to date!

Please keep those positive thoughts, prayers and messages coming!

Pieter and Alec julle is in ons gedagtes en ons wens julle baie sterkte! (Translated: Pieter and Alec, you are in our thoughts and we wish you much strength)

Notes: Again I had to rely on Heidi to do an update. It was a rather frustrating day that day, with Alec's file being missing, then the waiting – the endless waiting, getting into the C/T scanner and then finally getting to the doctor. I remember the doctor looking at the plates, then asking us to go and sit and wait in the passage, no other patient going in to his room, him finally going out of the room. He was away a good half an hour, and upon his return his whole demeanour changed. He indicated to us to enter his consulting room. He asked us what we wanted to hear, and I answered "the truth, nothing but the truth". He said to me that he had been working with HIV patients for 13 years and it was the first time in his life that he had seen such a healthy looking HIV patient who was in fact so ill. The lumbar puncture now needed to be performed immediately, right there and then in his rooms.

I'll never forget the fear I had in me when I saw the needle that they were going to push into Alec's spine to do the tap. And I had to help with it. I was scared beyond compare. What if Alec reacted to the pain and jolted? He could have been paralysed after that.

The doctor told me that Alec had had a multiple infarct or a series of small strokes over a period of time. But he also indicated to me that all were treatable; they just wanted to run more tests and for that they had to admit Alec to hospital. So after taking Alec to the ward where he was to lie, and settling him in, I had to go back home to fetch his pyjamas and slippers and toiletries.

The best news today!

5:11PM, Monday, 25 Feb, 2008

Hello everyone – heidil here again!

As i type this, i have a lump in my throat! The doctors have discovered the cause of Alec's aphasia and are now preparing to treat it! It is treatable and curable, and while it may take some time for him to fully recover, recover he will! Yes friends, Daddy A will be back soon to brighten our lives with his poems and very interesting pics!!

Pieter phoned me a short while ago to pass on the good news! He had just been to see Alec in hospital, and Alec was able to speak longer sentences and most positive is that Alec was asking questions like will he be able to write again and will he be able to speak again! This is a very positive sign and we are all very happy about this.

Recovery will take some time, so please keep carrying these two special "Daddies" in your thoughts and prayers!

Once again Pieter has asked me to thank everyone for your support, calls, prayers, sms's, comments, emails and the positive thoughts you have sent them. They are both very overwhelmed by everyone's kindnesses!

Pieter will be with us again tomorrow, and will tell you everything in his own indomitable way!

So my 2 blog buddies – i raise my e-glass of champers to you both! You have gotten through the worst part, the waiting and the not knowing part, now comes the recovery part, and from what i can ascertain, recovery will be slow, but steady!

We love you guys!!!!

Notes: Looking back, I realise that today was the day that our roller coaster ride officially arrived. Looking back I realise that the doctor was not 100% honest with us. Why I don’t know. We did ask him to be honest.

Alec looked very alone where he lay in the hospital. I felt as if I had failed him somehow, by allowing him to lie in Tshepong. But I also realised that we had to get to the bottom of this as soon as possible, in order to help him. I tried to visit Alec at every opportunity. I took him magazines, nice snacks – anything that would make his stay more comfortable. I tried to stay as long as possible. Somehow I preferred going on my own. It meant more quality time for us. Though it did not always work out the way I wanted.

Tuesday morning

8:18AM, Tuesday, 26 Feb, 2008

Good morning, all

Many many many many many thanks for all your well wishes, thoughts, prayers, dedicated posts and for being there for Alec and I. Without that, I do not think I would have been able to cope with what Alec and I are facing. Also a special thanks for Heidil for keeping you guys updated on my behalf.

In the past week I have learnt a *lot* of valuable life lessons. I think the most important lesson I have learnt is that Google is *not* a doctor. Whilst it is useful to type in symptoms and get a shortlist of possibilities, Google has *no* compassion. What you find is stark and harsh realities given to you without any emotion or compassion. Also, it gives you possibilities, not diagnoses. I have had the most horrifying few days after I did my Google searches and will *never ever* do so again. Yes, once a doctor has given one a diagnosis *then* you can Google and read up on it on how best to assist the patient. And I sincerely hope that this might be a lesson to someone else out there too. Nothing wrong with being inquisitive *but* don't overdo it. I did! And I think I aged visibly from Wednesday till yesterday.

Alec has suffered a multiple infarct. What it is, in laymen's terms, is a series of small strokes over a period of time. It is treatable, but recovery *might* be slow. We now have to establish what has brought it on hence the lumbar puncture yesterday. I am positive that in Alec's case it will be quick because of all the positive cognitive signs he is showing. There is also a slight improvement in his speech and he is speaking longer and more comprehensive sentences. He also does not have to think so long any more to get to an answer. Yes, there are relapses, when he gets frustrated, but I keep on reassuring him that he has to be patient with himself and keep on believing that he will get better.

I did speak to the hospital early this morning already and it appears he had a good night's rest and that his condition is stable. I sure can't wait till 15:00 to see him again.

Last night Anne and I went through to see him and he *sooo* much enjoyed seeing Anne. Anne – again thank you so much for being there for us. Although I did sleep last night, it did not feel right without Alec there. But Jessy made up for it by sleeping on the bed with me.

Another valuable life lesson I have learnt, is that you can never say enough times to your loved ones that you love them. Life is short and in the blink of an eye, you can lose someone. We all know that, but do we *realise* that? Never take your loved ones for granted, and never miss an opportunity to tell them that you love them.

And lastly – I have learnt that a stranger is a friend you don't know. And this was proven to me by you, my readers. So many thanks for all your support. Thank you Lord – for teaching Alec and I all these lessons, and for all our blog friends. Bless them as You bless us. Amen

Love
Pieter

Notes: By now (you will have noted) I had remarked enough about the fact that you need to love your loved ones. In a sense it can be seen as the birth of LYLO, though not really, as it would be a while still before LYLO would be born. But by now I had already started making people aware that they should love their loved ones. LYLO being an acronym for Love Your Loved Ones.

A funny thing was that Annemarie walked through security with a loaded gun and they did not pick it up. Security at the hospital frustrated me – they were not consistent – because sometimes you had to wait for ages before they would let you through the security gates, but my frustration really lay in the fact that I wanted to be with Alec and I felt they were keeping me from him.

By special request

9:59AM, Tuesday, 26 Feb, 2008

Good morning blog humans

I have not blogged for a while since Daddy P and Daddy (A) were frantic. However, here I am. I feel it is important that you all know that Milo and I are taking great care of Daddy P whilst Daddy A is in hospital. Last night, after Daddy P came back from hospital, he just fell onto the bed with his clothes on. He took one of those pink pills which he says is a tranquiliser and fell asleep. Milo and I figured that since Daddy A is not there, we would both sleep on the bed next to Daddy P to comfort him. Daddy P did not chase us off.

I also make sure that I sit constantly on Daddy P's lap whilst he is working, just to make sure that he is not alone.

Daddy P must work now – *plenty* to do so we will both see you a bit later

Love
Jessy

Notes: As mentioned I started blogging under the pen name, Jessysjungle, named after my Jack Russell Terrier. My readers wanted to know how Jessy was, since she had been impregnated by Milo, Alec’s Jack Russell. On this day Jessy made her reappearance to reassure her readers that she was alive and well and looking after her Daddy P.

Both dogs were a comfort in those early days. At night I would allow them onto the bed, something that Alec and I actually tried to discourage since Jessy was pregnant. But having them next to me gave me a sense of security.

Tuesday afternoon

1:00PM, Tuesday, 26 Feb, 2008

Hi there

Nearly on my way to the hospital. Feeling a bit lethargic but I ascribe it to the possibility that it is just exhaustion from the period where we just did not know what was going on.

I think the one question in everybody's mind at the moment is "But what about the wedding". Well, I have taken a decision that I first want Alec to heal properly so sadly it is postponed until a later date. Alec and I now first have a recovery route to walk.

What I can say is that now, more than ever, I want to marry this man. If anything came out of this ordeal, it brought us sooo much closer.

Liz asked if it is the same as a big stroke. I really do not know. All I know is that I am hopeful for a speedy recovery. Big strokes do a lot of damage (I lost a mother and grandmother to strokes). This multiple infarct is not as debilitating as a big stroke. In fact, we initially ruled out a stroke because there were no typical stroke symptoms, except for the stuttering. Normally you can pick up paralysis on one side of the body in a normal stroke and Alec had none of that.

But then, I am no doctor, so we shall be led by what his doctor says.

I'll give all your regards to Alec this afternoon.

Take care

'Pieter

Notes: I was feeling a bit exhausted on this day. Worried. When I arrived at the hospital Alec was a bit upset because the shower in his ward was out of order and he felt dirty and needed a bath. And his lips were all swollen, cracked and dry. I set off to the nursing station to enquire where we could go so that the man can have a shower or a bath. They arranged that Alec and I can go to the next ward so that he could have a bath. They could not explain his swollen lips. He enjoyed this bath tremendously and I assisted where I could – by washing his hair and his back for him. After this bath Alec gave me such a big hug and a big fat sloppy kiss.

It was also during this time that I noted that black people do not really understand or comprehend a same sex relationship. When the nurses, for instance, asked me what my relationship with Alec was, and I used the term Life Partner, they went all blank and then asked "Brother?" That's how Alec and I became brothers, it was just easier. And I saw one of his specialists that day – his name escapes me – whom I had to lecture about civil unions and constitutional rights because at first he would not speak to me about Alec, because according to him "we were not family".

I also explained to Alec that day that I had decided to postpone our wedding, which had been set for the 15th of March. He was upset about it, but understood. I made a promise that as soon as he was better, we would have a wedding. It was a very difficult decision for me to make.

Because the afternoon visiting time had been so draining, and because of the fact that since the Sunday I could not keep anything in when I ate, I phoned one of my dear friends, Peter Raubenheimer, and asked if he would mind visiting Alec with me that evening. He picked me up and we drove through. Upon arrival at the hospital I asked Alec if he could remember Peter (a little cognitive test) and Alec seemed quite perplexed that I would ask him such a stupid question. He was happy to see Peter and made sure that he showed Peter the flowers that his wife, Magda, sent with me that afternoon to the hospital.

I did one thing wrong that day, which Peter later corrected me on. Peter has been a counsellor with a support group for many years and was able to assess situations and advise me on how to handle them. Alec was crying whilst we sat outside and I held him and tried to comfort him and told him he should not cry. On our way home Peter corrected me and said that Alec had all the right to cry, I should rather have told him that and asked him why he was crying. I never again said to Alec he must not cry after that night – I encouraged him to get it all out.

Alec enjoyed it so much when I came to visit, because it meant that we could smoke a cigarette or two together. After our cigarette, we went back inside. I was wearing a pink T-shirt that day. I had taken along a clean T-shirt, so I took the pink one off and put the new one on. I wanted to leave the pink one there so that Alec could smell me in the T-shirt. He put it on the pillow I took along for him, with a huge smile on his face – he knew then that I had not deserted him.

Wednesday morning

8:08AM, Wednesday, 27 Feb, 2008

Morning all

I am very despondent today. When I arrived at Alec yesterday afternoon it appeared as if his situation has deteriorated. His lips were swollen, he was very confused, could not remember his name, could not remember which day of the week it was, and he was just very upset in general.

He was unable to take a bath because the ward bathroom has no running water. I had to take him to the next ward to have a bath and I helped him with that, washed his hair, washed his back and he did the rest himself. After the bath he appeared more settled.

Then I set off to get some answers. At first they said that they can only talk to family. Alec has no family, I am his only family, so I just lied and said to them that in terms of the constitution we are in a civil union, which makes me his husband and therefore his family, after which they called his specialist for me.

He arrived duly and explained to me that the lumbar puncture tests came back negative, which is a good thing, but that they are not any nearer to an answer. Explained to me that Alec now had to undergo a MRI Brain Scan which they would do sometime yesterday afternoon or today.

Although I remain all smiles and positive in front of Alec, I cracked up when I left there yesterday afternoon.

Yesterday evening, because I was still very upset, a friend took me to hospital and when we got there Alec was sitting outside a bit – which was a good thing. He was very glad to see us and got very upset when I asked him if he could remember Peter who went with me. I thought this was a good sign. Prior to going through, I had a long talk and crying session with HeidiL (God bless her soul) and she suggested that perhaps Alec looked so bad because he feels we have left him to fend for himself. So she suggested I take some familiar items with me to Alec.

So I took: One of his pillows, a photo of me and Jessy, the copper wrist band and "bravery" necklace we received when we did the Bungee at Vic Falls and his teddy bear. I also took a clean t-shirt for me and whilst there, took the one off that I was wearing. Perhaps being able to smell the t-shirt when I am not there, will give him some reassurance that I am close by.

With visiting time they still have not done the MRI, but when I phoned this morning to check in on him, they said he has gone for the scan. I'll get those results this afternoon.

Now how am I feeling? I am tired. I hardly slept last night, was up and about by 4:30 this morning and actually had a good crying session. I have not eaten since Sunday, I just can not take anything in. I tried a chicken sandwich last night but three quarters of it went to Jess and Milo, who thought that they were in Doggy heaven, getting such a treat. I drank some Bioplus this morning just to get some minerals in.

Dad's GF has taken over cooking from me so that helps a bit.

Please keep on praying for Alec, please. So that he may soon be better.

I'll try and have a good day and my wish for you all is a *fantastic* day.

Take care

Pieter

Notes: That came as a great help – Martie taking over the cooking for me. You can imagine that things were very hectic. Running a business, visiting hours at 15:15 and again at 19:00. And in between, cooking for three people and two dogs – even though you yourself weren't hungry and could not keep anything in. When I told Alec that Martie had taken over the cooking, I could see that he was pleased about it. It was comforting, but also heart wrenching to see that Alec was concerned about me too. I mean, in his condition, he still had enough energy to be concerned about me too. I'll never forget that.

Babies

9:20AM, Wednesday, 27 Feb, 2008

Hi All

Thanks for all your thoughts. I realise one can never say that (thank you) enough.

Some life emerged from the ground today. We are the proud parents of seven baby tortoises (possibly more to come). Dad discovered them this morning.

So now we can notify Nature Conservation that we've had some births, and in about a month's time they will come and fetch them and take them to a sanctuary. I do hope Alec enjoys this news this afternoon.

Take care

Pieter

Notes: We kept three mountain tortoises – one male and two female. They produce around fifty offspring in a year, and this was always the cause of much excitement around the house. With me being despondent about Alec, a few fellow bloggers at this point regarded the baby tortoises as a sign of new life, suggesting that it was an indication that Alec would get better. I was desperate for any sign and believed it.

Wednesday midday update

12:41PM, Wednesday, 27 Feb, 2008

Hi there
I had such a good crying session now you can't believe. The whole morning I was feeling miserable and despondent, and so, at 11:45 I decided to phone the hospital to hear how Alec is doing. The sister answered and I explained who I was and that I wanted to know how Alec was.

So I hear her speak to Alec's specialist in the background, and he says something like, oh that white guy, yes I remember him. Okay. So now I got a fright because I think the specialist wants to talk to me. And I wait and I wait. A good two minutes.

I hear the phone being picked up and a "hello". And then it struck me that it is Alec talking. And he spoke *soooo* well, coherent and comprehensive. Still struggling but 200% better than yesterday! And he told me that he loves me.

Alec, one day when you read this blog, you will realise how happy you made me today!!! After the conversation I just put down the phone and started crying. Not out of despair, but out of relief.

And I immediately asked Dad's GF to conjure up two eggs for me with tomato and brown bread. As I said, I have not eaten properly since Sunday, and I now have to treat the tummy respectfully.

Now the time must fly till 15:00. Can't wait to see Lekkie (my new nickname for him).

And oh yes, there are now twelve tortoises. Batty, you asked if we knew there was a nest. Yes, we work with Nature Conservation and we actually mark the nests (if we see them digging nests, that is). Don't think more will emerge from this clutch though.
Have a Fabulous Wednesday all our friends. Till later.
Pieter

Notes: I got quite a fright when I waited so long for someone to come on the line. I actually thought the specialist wanted to talk to me, to tell me that Alec had passed away or something! So I was very surprised when Alec answered the phone. He tried to tell me something but I could not make out what he was trying to say. I said I'd see him at 3:00 and again he tried to tell me something, that he would be going away but I did not understand all of it. It was something to do with the MRI scan (Magnetic Resonance Imaging) so I told him that I knew he was going for the scan and it's okay. If he was not there when I arrived I would go and look for him. Again he tried to warn me but either he could not find the words or I could not understand his difficult speech. And then I told him I loved him and I could hear the smile in his voice and he said loud and clear "I love you too".

I put down the phone and just started crying. Tears of relief.

I went to the hospital at three only to find that Alec was not there. I asked if he perhaps had been moved to another ward and they told me that Alec had gone for his MRI scan. I asked them where that was and they pointed me in the direction of where they do the C/T scans. I went over to that section of the hospital, only to find that there was no such facility at Tshepong. So I went back to his ward where I found one of Alec's doctors who told me that the MRI scans were done at Coronation Hospital, but he could not tell me where that was, other than somewhere on the Rand. Then the penny dropped for me – THAT was what Alec had tried to tell me, or warn me about. Even in his demented state (and I mean this in the nicest possible way) he tried to save me an unnecessary trip to the hospital because he knew he would not be there.

I was a bit despondent and upset that they did not let me know they were sending Alec off to Coronationville. I would have expected they would at least inform me about that.

I phoned the hospital shortly after 18:30 to find out if Alec was back from Coronationville. It would have been pointless for me to drive there and find that he had not returned. They told me that he had just came back, so I set off to visit Alec. When I arrived I immediately saw that he had a harrowing day. He had changed into new clothes. His old clothes were full of vomit. It must have been the effect of the magnetic currents that made him nauseous. I again felt disappointed that I had not been able to go along and BE there for Alec. I took him for a bath, as I did every night. I opened the hot water and then the cold water to regulate the temperature so that Alec did not burn himself. He just lay in the bath, soaking in the water.

After his bath I took him back to his bed and he immediately drifted off to sleep. There was a huge brown envelope lying on his bed tray so I decided to have a look. I read the report. I can not recollect everything the report said, but there is one sentence I will never forget – "the lesions are consistent with PML. Prognosis: Guarded." I did not know what PML was and undertook to read up on it the minute I got home. I sat with Alec for a while still – content that we FINALLY knew what was wrong with him and that they now could start getting him better. Little did I know that in just a half an hour from then I would discover something on the Internet that would shatter my hopes completely.

I returned home where Dad and Martie immediately wanted to know of Alec's progress, and I told them that they now think that they know what was wrong with Alec. I told Dad that I quickly wanted to look up what PML meant and then I would go and tell them. I googled PML and came across this information – which I read for them:

Progressive multifocal leukoencephalopathy

From *Wikipedia*, the free encyclopedia

Progressive multifocal leukoencephalopathy (PML), also known as progressive multifocal leukoencephalitis, is a rare and usually fatal viral disease that is characterized by progressive damage (-pathy) or inflammation (-itis) of the white matter (leuko-) of the brain (-encephalo-) at multiple locations (multifocal). It occurs almost exclusively in people with severe immune deficiency, e.g. transplant patients on immunosuppressive medications, or AIDS patients.

Cause

The cause of PML is a type of polyomavirus called the JC virus (JCV), after the initials of the patient in whom it was first discovered. The virus is widespread, with 86% of the general population presenting antibodies, but it usually remains latent, causing disease only when the immune system has been severely weakened.

About 2-5% of AIDS patients develop PML. It is unclear why PML occurs more frequently in AIDS than in other immunosuppressive conditions; some research suggests that the effects of HIV on brain tissue, or on JCV itself, make JCV more likely to become active in the brain and increase its damaging inflammatory effects.[1]

See also recent announcement by Roche US Pharm regarding PML and CellCept

http://www.fda.gov/cder/drug/early_comm/mycophenolate.htm

Contributing causes

There are case reports of PML being caused by pharmacological agents, although there is some speculation this could be due in part to the existing impaired immune response or 'drug combination therapies' rather than individual drugs. These include rituximab[2], infliximab,[3] natalizumab[4], chemotherapy [5], corticosteroids [6], and various transplant drugs such as tacrolimus.[7]

Disease process

PML is a demyelinating disease, in which the myelin sheath covering the axons of nerve cells is gradually destroyed, impairing the transmission of nerve impulses. It affects the white matter, which is mostly composed of axons from the outermost parts of the brain (cortex). Symptoms include weakness or paralysis, vision loss, impaired speech, and cognitive deterioration. PML is similar to another demyelinating disease, multiple sclerosis, but since it destroys the cells that produce myelin (unlike MS, in which myelin itself is attacked but can be replaced), it progresses much more quickly. Most patients die within four months of onset. PML destroys oligodendrocytes and produces intranuclear inclusions.

Diagnosis

PML is diagnosed by testing for JC virus DNA in cerebrospinal fluid or in a brain biopsy specimen. Characteristic evidence of the damage caused by PML in the brain can also be detected on MRI images.

Treatment

There is no known cure. In some cases, the disease slows or stops if the patient's immune system improves; some AIDS patients with PML have been able to survive for several years, with the advent of highly active antiretroviral therapy (HAART).

AIDS patients who start HAART after being diagnosed with PML tend to have a slightly longer survival time than patients who were already on HAART and then develop PML.[8] A rare complication of effective HAART is immune reconstitution inflammatory syndrome (IRIS), in which increased immune system activity actually increases the damage caused by the infection; though

IRIS is often manageable with other types of infections, it is extremely dangerous if it occurs in PML.[9]

Other antiviral agents that have been studied as possible treatments for PML include cidofovir and interleukin-2, but this research is still preliminary.

Cytarabine (also known as ARA-C), a chemotherapy drug used to treat certain cancers, has been prescribed on an experimental basis for a small number of non-AIDS PML patients. It is reported to have stabilized the neurological condition of a minority of these patients.[10] One patient regained some cognitive function lost as a result of PML.[11]

http://en.wikipedia.org/wiki/Progressive_multifocal_leukoencephalopathy

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That night I read up on PML for most of the night. And all the websites told me the same thing – death sentence. And I still did not understand. Perhaps they had interpreted the scans wrong. Perhaps Alec's immune system would reconstitute itself, if only the hospital could start that now. Perhaps they made a mistake. It was a government hospital so what would they know in any case. Denial in full swing.

Thursday morning update

8:42AM, Thursday, 28 Feb, 2008

Hi there all

Sorry I did not post an update yesterday afternoon after my 15:00 visit to Alec. Reason being, that when I got there, he was not there. It took me a good few minutes to establish that they took Alec for an MRI Scan in Johannesburg *without* telling me. Had Alec been called Alexis and a female and my wife, I would imagine they would have told me.

Anyhow – I went to visit last night and he was all comatose. He was *sooo* exhausted and all he wanted to do was sleep, so I let him be. I sat with him, prayed for him, brushed my hand through his hair. That kinda thing. I think the trip to Johannesburg and the MRI scan (Magnetic Resonance Imaging) exhausted him immensely. I brought his used nighties home to wash for him.

I phoned the hospital this morning and they allowed me to speak to him. He was a bit confused and not as clear as yesterday, but that does not mean the end of the world. I am 100% certain they will start treatment today now that the results of the MRI are available. I will speak to his specialist this afternoon about it.

Grab yourselves a wonderful day. And as always, love your loved ones as you do not know how long you will have them. And as always, thanks for the prayers, thoughts, emails, comments and calls coming this way.

Take Care

Pieter

Notes: When I wrote this post I was extremely despondent. I could not fathom or understand what I had read the previous night. I could not inform my fellow bloggers either what had happened to Alec. I had to speak to his specialist first. I was very much in denial.

That afternoon, I went to the Hospital and immediately after I set foot in the ward the nurse in charge of the ward told me that the doctor wanted to see Alec and myself. She directed us to his room and we waited for five minutes before he called me in first. He asked me if I knew what was wrong with Alec and I told him that I had read the report. He chastised me for doing so and I told him that it should then not have lain around for anyone to read. I told him that I was sure he would have done the same thing, had his wife been in Alec's shoes.

Both of us calmed down a bit, and he explained that he needed to get Alec's permission before talking to me, so he sent me out and asked me to send Alec in. I led Alec into his room and waited for less than a minute before the doctor called me back in.

The doctor told Alec that he had PML, and there was no cure for it. We could make an attempt to prolong his life with HAART treatment, but there was no guarantee that it would work.

We had two choices: 1. would we proceed with the treatment and 2. would we institutionalise Alec after treatment or would I look after him at home. We had to give him the final answer to the first question the following morning at 06:00. The second question I did not even feel bothered to answer but I did and said that there was no way that Alec was going to be institutionalised.

And that was it. Death sentence issued. No explanation as to what caused PML, no explanation as to what the treatment entailed.

Alec and I sat in the bit of garden the hospital had and I counselled him on PML. I explained how it worked, how he got it, what his chances of survival were. I held his hand all the time in both of mine. Alec cried a lot. I spoke about the treatment and he just shook his head, indicating that he did not want the treatment. I told him that I loved him, and that he must remember we were in this thing together, and I urged him to take the chance.

I reassured him that I would look after him and that he should not be worried. I focused more on the positive than the negative, and suggested to him that just maybe he was part of the 1% that survive. I explained to him about CD4 counts, about viral loads and what we could do to keep his CD4 counts up. When Alec looked me in the eyes, tears brimming in his, I could see that he trusted me, completely.

That day I promised Alec that he would not die alone. That death would not part us.

Visiting time was over and I walked him to his ward. On my way back to the car, the tears started to flow. My world collapsed. I phoned Heidi.

Not a very easy post to write – heidil

4:26PM, Thursday, 28 Feb, 2008

Hello everyone

Please please please keep Alec and Pieter in your thoughts and prayers. They need your support and encouragement and love and prayers now more than ever!

Pieter has just phoned me, he is unable to blog himself as he is very emotional at the moment, so i offered to do it for him despite the emotions welling up inside me. As i type i am holding back the tears, as this is not a very easy post to write.

They have finally been able to diagnose what Alec is suffering from, and the prognosis is not good. Alec is suffering from a very rare viral disease that attacks the brain. Only 5% of the population suffer from this disease, and at this moment there is no cure for it. They are going to be opting for a trial treatment which will give Alec a 50/50 chance of surviving. Without the trial treatment, Alec will only have 4 – 6 months to live.

As you can imagine Pieter is devastated by the news, and he needs your prayers just as much as Alec does, as he is Alec's only family. Everyone who has followed Jessy's blog since Pieter first started posting will know just how much he loves Alec, and how happy and in love the two of them are. Which one of us will ever forget the post in which Pieter asked Alec to marry him, and we all waited with bated breath to see what the answer would be? We have shared so many highlights with these two very special people and we have also shared many lows with them too.

I want to view this as another low that will turn into a highlight before the end of the year and i now ask you all to join me in a prayer for Alec, to give him the strength to face this challenge and to be positive about him being healed, as well as for Pieter who is going to need all the support he can muster to help Alec beat this thing!

Pieter, please know that all of your blog buddies are 100% behind you in this, and whatever you need, please do not hesitate to ask for. We are here for you.
Alec, ons is lief vir jou en ons weet jy gaan nie dat die prognose jou onderkry nie. Ons weet jy gaan die ding oorwin en gesond aan die ander kant uitkom. (Translated: Alec, we love you and we know you are not going to allow the prognosis to bring you down. We know you are going to defeat this thing and come out healthy on the other side)

To you both, as well as all Pieter and Alec's non-blogging friends, Oupa and Aunty M, much love and strength through all of this. With a positive attitude and armed with all the knowledge you have, the treatment will work.

To everyone in Blogland, thank you for all your support and prayers and please keep them coming.

Notes: I was extremely emotional, so I asked my friend Peter to take me to hospital again that night. Whilst driving there I played open cards with him and told him about Alec’s condition, what the specialist had said, how I had to counsel Alec, how traumatic it was for me. Peter just drove, he did not say a word.

We arrived at the hospital and went through immediately to see Alec. He looked perkier than the afternoon and we sat outside, having a cigarette. That night I brought our Bible along and started a ritual that would last until Alec’s death – reading 1 Corinthians 13. I remember reading it that night. I choked up, but persevered and carried on. Both Peter and I said a prayer. I also told Alec that things were looking up, as we had received a comment from a blog friend who suggested that he would be happy to pay for a second opinion, and that if things did not get better, we would take up this offer.

After visiting time we left the hospital. Peter made a turn that he wasn't supposed to make and I asked where he was going. He answered me he could go where he wanted. I left it, and the next moment he stopped off at a pub. He explained to me that he just wanted to get me out of my situation for a while. I phoned Dad to let him know that he and Martie should not wait up for me.

I really appreciated the gesture by Peter. Whilst in the pub one of my blog friends phoned me after reading Heidi's post. Peter and I had two whiskeys each. On our way home he suggested that perhaps I should consider a hospice taking care of Alec. I did not reply to his suggestion, but struck those words out of my mind immediately, as it was never going to be an option I would consider.

Friday morning update by Pieter

9:01AM, Friday, 29 Feb, 2008

Good morning, my dear dear dear blog friends

First of all a *huge* thank you for all your prayers and support. I do believe in miracles and so should you.

The news Alec and I received yesterday was very devastating. The doctor's finding was based on a c/t scan, an MRI scan and dependent on a blood test. All indications at that stage were that it is a rare but debilitating and extremely aggressive viral disease. Alec and I both received counselling and it was explained to us that there is no cure, and only experimental or trial treatment available. You read it all on Heidil's post of yesterday.

I had to be at the hospital at six this morning so that Alec and I could both give consent for treatment to begin. However, I did say that it was dependent on a blood test. The results were available this morning and a protein count in the blood points against the viral disease. There is however *another* viral disease that mimics the one the doctor spoke about yesterday, but that one is far less malicious and completely reversible. We have now proceeded with treatment against the second one and we will hopefully see a speedy recovery. If not, we're back to the diagnosis that was made yesterday

Alec was at his most coherent last night when I visited him. Had no problems with his cognitive side – remembered things instantaneously, and only had problems with speech.

I have to be honest – this past two weeks have been a roller coaster ride for me and the next week it will still continue. I do *not* want to get your hopes up *or* play on your emotions about this life/death situation, *but* let's hope that it is the second and not the first disease. Hopefully a speedy reaction to the drugs will confirm this, but we will have to be patient.

In the meantime, Alec did ask me last night and again this morning to thank you for your thoughts and prayers. And from the bottom of my heart, I say *Thank You*. Will keep you updated.

Regards

Pieter

Notes: Still I had not informed our blog friends that Alec was HIV+. The protein count in the blood test I referred to in my post actually referred to his CD4 count. I went to the hospital with trepidation that morning, scared that Alec might have changed his mind and opted against the treatment. He was so glad to see me – the most beautiful smile lit up his face when I walked into the ward. It was only a short while before the specialist came to Alec's bed – he was busy with his rounds. He broke the news to me that he was hopeful it might not be PML, but rather another disease that mimics PML in all aspects but fatality, called Demyelinating Encephalitis. This could be completely reversible. He based this opinion on the fact that Alec's new CD4 count had come back high and was not as low as the first time. Both of us were grateful to hear this news and the doctor said he was going to proceed with treatment for both diseases. I left hospital very hopeful that it was the second disease and not PML.

Friday midday

12:29PM, Friday, 29 Feb, 2008

Hi there

I am sitting here and I am overwhelmed. I am awed. I am humbled. And nothing I can ever say or do will be able to express my gratitude for your ongoing support, comments and calls. I am sure you can understand that I cannot reply to each message personally, but do know please, it is surely appreciated.

Curiosity got the better of me and I phoned to find out how Alec is doing. From what I can gather his vitals are good and he is sleeping. (Obviously with all the drugs they are pumping through him now).

Then back on the home front – another tortoise nest started to hatch and there are two more little baby tortoises. Sign of life, Miesies Frog, sign of life.

Checking out for now – I'll ask Heids to do an update at 16:00. I will phone her from hospital with feedback.

Take care

Pieter

PS: Have you told your loved ones today you love them? And meant it? I did.

Notes: I was very humbled by all the comments of support we received on Heidi's blogpost of the previous day. Someone had even offered to pay for a second opinion.

I couldn't wait to get to hospital that afternoon to see for myself how Alec was, since it was my firm belief all that needed to happen was getting the life saving drugs into Alec.

16h00 update – heidil

4:11PM, Friday, 29 Feb, 2008

As i type this, i am smiling and am glad to be the bearer of glad tidings from Quiet Fountain this afternoon!

Alec has finished the first treatment, and as Pieter and I were chatting, the hospital staff was preparing to replace his drip with the second treatment for the day. So far Alec has not had any adverse reaction to this medication, so no nausea or any nasty side effects.

Pieter says he is looking the best he has seen him since this whole nightmare began, and Oupa, who hasn't seen Alec since he was admitted to hospital, remarked how well he was looking. Alec was able to remember things that Pieter had told him this morning – which is a marked improvement! He recognised Pieter and Oupa, and only struggled a little with his own name.

I believe in Miracles, and I am convinced that it is the support and prayers of everyone in Blogland (as Glink said – they are creating a glow in the sky) who have brought them thus far. As it is early days yet, and there is a long road that still needs to be walked, we need to continue to uphold our dear friends in prayer!

To Believe ...

By Unknown

To believe is to know that every day is a new beginning. It is to trust
that miracles happen, and dreams really do come true.
To believe is to see angels dancing among the clouds, To know the
wonder of a stardust sky and the wisdom of the man in the moon.
To believe is to know the value of a nurturing heart, The innocence
of a child's eyes and the beauty of an ageing hand, for it is through
their teachings we learn to love.
To believe is to find the strength and courage that lies within us.
When it is time to pick up the pieces and begin again.
To believe is to know we are not alone, That life is a gift and this is
our time to cherish it.

To believe is to know that wonderful surprises are just waiting to
happen, And all our hopes and dreams are within reach.
If only we believe.

Notes: My Dad went with me in the afternoon to visit Alec. We sat outside the ward in the sun to have some privacy. Alec was on a drip so we had to roll the drip stand along outside. Alec had this huge beatific smile on his face when we walked in and he saw Dad. He said “Hallo, Pappa” and my heart just wanted to burst. Alec had started calling my Dad “Pappa” or “Pappie” from probably the day we moved in together. It was a good visit that afternoon. Alec could also remember things that were discussed that morning and questioned me about it. It was to me, at that stage, an indication that his short term memory was still intact. or at least getting better.

Upon arriving at Alec’s bed the evening I found him asleep, so I just sat and stroked his arm. The other patients in the ward just stared at us. Alec woke up and was very confused and agitated. He wanted to go home. Instead I whisked him off outside so that he and I could have a cigarette before he went for his bath. And afterwards we had another cigarette, and then we read from the Bible and prayed. We did not mind who saw us holding hands whilst we prayed. We were not bothered.

Saturday morning update

8:21AM, Saturday, 01 March 2008

Hi there all

Thank You still for all your messages, thoughts, prayers, karmas, emails, phone calls. I am a bit overwhelmed by all the support and grateful for it to help us through this very trying time.

Went to visit Alec last night and when I arrived there he was asleep. So I just stroked his arm for a while. He was a bit confused when he woke up, but how many of us are not? I did sense, however, that the medication made him a tad more confused than normal.

We went and sat outside for a little bit of privacy. Only complaint he had was that of experiencing a floating feeling. Checked his vitals earlier in the ward, no high blood pressure or pulse, so it must be a side effect of the medicine, I explained to him.

Outside he was very coherent. A bit impatient because he wants to be at home now, so I explained that there are four more days of treatment and that he would be home real soon. Then I broke the news to him. HeidiL is coming to visit us. *All* the way from East London. He was so excited he started to cry. But I know it was a cry of gratitude (I have become the master of reading his tears – when it is tears of joy, gratitude or frustration).

Hospital said this morning he had a good night. We'll see later.

I did not have a good night though, in part. Seems my ulcer wants to start up again, nothing like good old Zambuk to soothe that. Looking forward to today - Anne is coming to spend the day with me and Alec can't *wait* to see them. I get the impression he lives for visiting hours.

Again guys, girls, blog friends.
Thank you for being there for us.

Have a good Saturday. And tell your loved ones you love them. Please.

Pieter

Notes: When I phoned Tshepong that morning they warned me that Alec might be transferred to another ward. The ward he was in first (ward 4), was a Highish Care Ward where the medical personnel decided what was wrong with you before you were transferred out to another ward. They said I must first check if he was not still there when I arrived at visiting time. Just as well I did – because half of Alec's belongings were still in his previous ward.

Annemarie and Simone came through to Stilfontein from Potchefstroom so that they could make the afternoon visit with me, and as always Alec had that angelic smile when he greeted Annemarie and Simmi (we call Simone by her nickname Simmi) and called them by their names without any stuttering or hesitation. All Alec kept on asking was when he could come home and it felt unbearable for me to leave him there.

Saturday evening update

9:22PM, Saturday, 01 Mar, 2008

Hi All

Phew! What a day. I am exhausted, I'll be honest. But you're not reading this to find out how I feel physically. You want to know how Alec is doing. Right?

I am guardedly confident that Alec is responding well to the treatment. He was today, at both visits, the *best* I have seen him this week. He saw Anne before he saw me and said, without having to think or without hesitation – Hello, Anne. Loud, clear, in control.

He looked so alert, with it, together, collected, I nearly burst out crying out of joy. *Okay*, we still have a very long way to go, but every day is one step in the right direction. He is just a little bit impatient and wants to come back home now. If only I could tell him how *much* I wanted him home – but I do not want to add to his stress.

He has been transferred out of his ward to another ward. This first ward was a sort of high(ish) care ward where they first stabilise you before you are transferred out to another ward. The new ward has showers and baths, not only baths. And tonight I took Alec to shower. He was like a kid. A big kid. Both of us prefer showers to baths and he just could not get enough. I think it also helps him to feel better. I also made him some Bobotie and he devoured that like a lion who hadn't made a kill in two years.

Me. I am hoping to get a good night's rest, especially since my ulcer showed up for the first time in three years last night and kept me up. However, I think it was just my body's way to say "look after yourself" and so I started to listen. I feel much better today than last night.

I said to Anne today this whole thing with Alec is just a test of my faith and to bring both Alec and myself closer to God. I am glad that we are worthy of such a test.

On the home front – two more tortoise nests started to hatch today and we now have a grand total of 26 tortoise babies! Little critters – you have to look so carefully to find them once they have taken cover! But they are so cute. Alec can't wait to see them, but refuses to let me take one to hospital with me to show him. And Jessy (yep – she is still here) is really ballooning out now. And she is ever so loveable. And Milo, all of a sudden, has taken to sleeping inside the washing basket. Sure he misses his dad. Maybe I should get into the washing basket with him to show him some solidarity.

Guys, girls, once again – thanks for your thoughts, your prayers, your comments, your concerns. 2 weeks ago I would never have thought that I would need them so bad as I do now. *Thanks* for not failing us.

And don't stop praying, please, it’s not over yet. We still have three days to go.

Love your loved ones!!!!
Pieter

Notes: I firmly believed that Alec’s condition was just a test of my faith. Of **OUR** faith. Perhaps it was denial; perhaps it was because Alec seemingly started to get better. Perhaps I did not notice the deterioration then. Perhaps I remained positive – not only for my sake but also for Alec. I told Alec about all the comments he had received on my blog, all the *get well soon* messages, all the *speedy recovery* wishes. And Alec was as overwhelmed by them as I was. I could tell that Alec was hoping to blog very soon, so I asked him if there was a message he wanted me to pass on to all our blog friends, and it was with tears in his eyes he said thathe gave a message to pass on.

Alec was very excited about the new ward’s showers. That night I took him for a shower, making sure the water temperature was just right so that he did not scald himself, and for about 5 minutes he just stood in the shower, allowing the water to flow over his body. I then handed him his shampoo so that he could wash his hair, and then his shower gel.

Sunday morning

7:41AM, Sunday, 02 Mar, 2008

Hi there all

Glad to report I had a good night’s rest and that I actually look forward to today. And this week.

I am sure that Alec will be discharged on Wednesday, *just* in time for Heidil's visit! But I am not putting my heart onto that – just hoping it will be like that.

Spoiling myself a little bit today by remaining in bed a little bit longer than usual. At about 10:00 I'll start lunch (roast chicken and others) so that I can take Alec some when visiting him at 15:00. Also have to rinse out a couple of things for him.

I forgot to mention last night, forgive me. When I asked Alec if there was any message he want me to pass on to blog land - he had tears in his eyes and just the words "baie baie dankie" – Thank you very very much.

Wishing you all a stunning Sunday. Will phone the hospital in a bit. And to echo Alec's words – Baie, baie Dankie!

Love
Pieter

Notes: I was very grateful for the support we received from our blog friends. Complete strangers who sent us wishes. I decided on this day that I was going to take Alec some lunch and prepared one of his favourite meals, roast chicken. Subconsciously I think I have also let down my guard a bit, seeing that Alec looked so much better the previous day. In those days, I grabbed at every little straw there was to grab.

Sunday mid morning feedback

10:41AM, Sunday, 02 Mar, 2008

Hi all

Just spoke to the hospital and they say – hear this – Alec says that he feels *much* better. Alec says, they said. They however could not tell me if his speech has improved, that we will see this afternoon. And because he is on his daily drip – they could not call him to the phone for me either. But that's okay. I believe in miracles, and I will keep my belief firm that it is the case.

I may or may not have mentioned that I believe in a God of love. And therefore I believe this God of love will not destroy what Alec and I have built up in such a short period of time without any good reason. And therefore I believe Alec *will* be okay and will recover swiftly.

On the home front – 10 more baby tortoises came out last night, making the total 36 so far. Someone asked how big they are – they are about 4 to 5 centimetres in diameter. Sweetest and cutest little things. But they are popping up all over the show this year. Did you know that the eggs take more than a year to hatch?

Well – off to shower now, then the Spar thingy, then food, then hospital with Sussa so that we can see Alec's progress. I do hope to give you guys miraculous news this afternoon. I have a gut feeling I will, but I will remain humble enough to wait. And see.

Thanks for keeping us in your prayers and thoughts. And remember – tell your loved ones that you love them!!

Love
Pieter

Notes: I was rather excited when they told me that Alec said he felt better. It gave me some hope and some inspiration. Understandably because it was his first 24 hours in the new ward, they could not really tell me if Alec's speech had improved or not because they had nothing to compare his speech against.

My sister and her youngest daughter made the visit with me to Alec that afternoon. I could see that both of them were visibly shaken by what they saw, but I begged them beforehand not to say anything about his condition in front of Alec. Alec had a very soft spot for both of them and was very happy to see them. Alec enjoyed the roast chicken so much, but I did notice something strange when he ate – it was as if he ate too fast and stuffed his mouth like a little chipmunk would do. And that he then struggled to swallow the contents. I remember I was concerned about it, because I was scared that he could choke. But I shrugged it off as a side effect of the HAART treatment he was on. Little did I know that what was happening was that the area of his brain that controlled his swallowing reflex was busy being destroyed.

On our way back to the car my sister asked me whether Alec had Aids. I explained the difference between HIV and Aids to them and explained that Alec's CD4 count was too high for him to have Aids. That's how ill informed I was myself – either that, or ignorant, or in denial, because after Alec's death I would learn that PML is regarded as an Aids Defining Event. They were very concerned about me.

That afternoon it looked as if a major rain storm was approaching, and in his own way Alec tried to indicate to me that if it rained, I should not drive through to visit him. But the storm had passed by the time I visited him again that evening. Whilst I was there another huge storm erupted, just as we went to have his shower. There was a window high up in the wall, and from where he stood he could see the orange glow of one of the security lights on the hospital property, which was highlighted by the rain that fell through the glow. Alec pointed at it and said "mooi" (pretty). When I asked him to mix his water to the right temperature, he indicated that he couldn't, he didn't know how to – this was a little test that I threw in, which at the time was important to me as it indicated his reasoning/judgement abilities.

We then went outside and in the doorway he looked back to see if there was anyone behind us, and then looked forward to see if there was anyone in front of us – after he established that the coast was clear, he grabbed me and gave me such a big hug and kiss. He was like a young child in his innocence.

That evening, after visiting hours were over, he walked all the way down the rather long corridor with me. All the signs I received that day indicated that Alec was getting better.

Monday morning update and our Wall of Support

9:00AM, Monday, 03 Mar, 2008

Morning, All

Now I'm not as adept as Lyndatjie or HeidiL or the rest of you when it comes to being creative, but below is a wall Alec and I have built around ourselves. All of you are bricks in that wall. Thanks for that. You will note that though every brick has a special meaning, there has to be a foundation. And there have to be cornerstones. The first layer of bricks has to be the strongest to carry the rest of the wall. So first all my and Alec's thanks to God – then To Lyndatjie and HeidiL. Ride The Slide for his very generous offer, MissTiGGeRr and Xena. And *all* of you who helped carry us through this ordeal. I am sure I have left people out and I do apologise about that, hence the brick "Those I forgot to mention".

XAM	Getmeout	Casper	Those I forgot to mention – sorry	
Stray cat	Sandlover	FairyBell	Granny	Buky
Ina	Rachel	Annemarie DB	Jack	Kingfisher2
Dad	Martie	Joannevdm	SBM	Saul
Petro	Emile	Susurration	Ramona	Magda
Blommie	Tear Drops	Interloper	Old Hen	Peter
Joey	Vonette	Adele	Quinton	Daaivark
Wizard	Rose	Kerneels	Annemarie	Simmi
MP3	Italian	Alistair	Sibahle	Glink
Aquarius	Nur Ich	Ambi	White Feather	Lisa 04
DT	Champagne	Whisperer	Dinx	DreamWeaver
Croco	Nattie	The Runt	Miesies Fr©g	Mrs. C
Blue	Cat Woman	Wicca Girl	Relic	Marcy
Poppiekreer	Colonialist	Lornagh	Batty	Hutton
Piet	Butterfly	Lady Bug	Kleine Vlieg	Napier
Yasdia	Silent Noise	Kim Stories	Supagran	Gorme
Heath	pmbman	Blanket	Jhani	Madmom
Lyndatjie	Ride The Slide	MissTiGGeRr	Xena	Heidil
GOD				

So, how is it going with the man? Yesterday morning I phoned and they said Alec said he feels much better. Arrived at 15:00 and I found Alec a bit confused, but that is because he was on a drip. He thoroughly enjoyed the roast chicken I took along though. Last night's visit went much better – he enjoyed his shower and he had the first very clear, pre this condition's Alec words – "Ek weet nie hoe nie" / I don't know how. Loud and clear and without hesitation, without stuttering.

Which leads me to be as bold to ask that when we pray for Alec, we also pray for the speedy recovery of his linguistic abilities and for the healing of the scars that have brought this along.

The "death sentence" is still hanging over us, yes, but we are more optimistic than ever that it was rather the second diagnosis than the first. And so far Alec has not shown any negative side effects to the treatment other than having a floating feeling when he is on the drip.

I phoned this morning, they said that Alec is up and about and having breakfast at the time I phoned.

Then I also have a request. Xena has been so kind as to create a candle lighting group for me and Alec. Please Light a candle on Xena's Blog. Namaste Xena.

Wishing all of you a beautiful Monday. And remember – *tell* your loved one's that you love them. And mean it.

Love
Pieter

Notes: This blogpost was done to show our gratitude to people we did not know. It was done to say Thank You to them. All over South Africa, and even overseas, there were prayer chains being set up for Alec. People dedicated special blog posts to us, lit candles and sent Reiki healing our way. Telling my Dad about it, amazed him as well. He could not believe that complete and utter strangers could care to the extent they did. Fellow bloggers told me how big their prayer chains were, and I would relay that information to my dad.

A post from Jessy

11:20AM, Monday, 03 Mar, 2008

Hi there, blog humans

Been a while since last I posted, but I'd thought Daddy P would allow me to post today. So here I am.

I need to give you some feedback. My pregnancy is progressing well. Daddy P said I have gained just over 2 kilograms already. I am very uncomfortable I have to be honest and I cannot decide at night whether I must sleep underneath or on top of the duvet. And when I do want to fall asleep it is as if I can just not find the right position. And it is very sensitive on my tummy when Daddy P rubs it. *But* he did something last night – he massaged my back! Now *that* was most enjoyable and I wish he'd do it more often. But Daddy P teases me a lot. Says something about my breast size and me wearing a bra. Says by the looks of it I would need a 38DD one of these days. What he does not know is that they are beginning to feel painful and I wish he would be more understanding of all that I am going through just to give him and Daddy A some grandchildren.

About Daddy P. Milo and I are really taking good care of him. Milo guards the room from his hide-out tower – the washing basket, and I comfort Daddy P, pretending it is Daddy A lying in his arms. And don't he dare chasing me off the bed whilst Daddy A is still in hospital – I just ignore him. And when he goes to the office, *both* of us are with him. The only time we're not with him is when he goes to hospital.

Love
Jessy

PS: Have you told your loved ones that you love them lately? I know I told Daddy P this morning and he told me.

Notes: Jessy was well advanced with her pregnancy and most of our blogging friends asked how she was, so I "afforded" her the opportunity to inform our blog community herself. In honesty, both dogs were guarding me like angels. I could not turn or they would be there. And if they could go with me to the hospital, I am sure they would.

For Alec – from Pieter. "Ne Me Quitte Pas" – Jacques Brel

12:09PM, Monday, 03 Mar, 2008

All of you know that Alec and I have rather eclectic music tastes. I was listening to some music now when this one came up. So I dedicate this to Alec. I'm sure that one day soon he will be able to read this and listen to this.

So I share it with you too. Hope I get it right. (OK, obviously not – sorry – just click on the link to go to the video in Youtube). For your ease, I have put the French words as well as the translation below.

Love
Pieter
http://www.youtube.com/v/uEAGoLHMMoA

Don’t leave me now

Don’t leave me now
We must just forget
All we can forget
All we did till now
Let’s forget the cost
Of the breath we’ve spent
Saying words unmeant
And the times we’ve lost
Hours that must destroy
Never knowing why
Everything must die
At the heart of joy
Don’t leave me now
Don’t leave me now
Don’t leave me now

I’ll bring back to you
The clear pearls of rain
From a distant domain
Where rain never fell
And though I grow old
I’ll keep mining the ground
To deck you around
In sunlight and gold
I’ll build you a demesne
Where love’s everything
Where love is the king
And you are the queen
Don’t leave me now
Don’t leave me now
Don’t leave me now

Ne me quitte pas

Ne me quitte pas
Il faut oublier
Tout peut s'oublier
Qui s'enfuit deja
Oublier le temps
Des malentendus
Et le temps perdu
A savoir comment
Oublier ces heures
Qui tuaient parfois
A coups de pourquoi
Le coeur du bonheur
Ne me quitte pas (4 fois)

Moi je t'offrirai
Des perles de pluie
Venues de pays
Où il ne pleut pas
Je creuserai la terre
Jusqu'apres ma mort
Pour couvrir ton corps
D'or et de lumière
Je ferai un domaine
Où l'amour sera roi
Où l'amour sera loi
Où tu seras reine
Ne me quitte pas (4 fois)

Don’t leave me now	Ne me quitte pas
For you I’ll invent	Je t'inventerai
Words and what they meant	Des mots insensés
Only you will know	Que tu comprendras
Tales of lovers who	Je te parlerai
Fell apart and then	De ces amants là
Fell in love again	Qui ont vu deux fois
Since their hearts stayed true	Leurs coeurs s'embraser
There’s a story too	Je te racont'rai
That I can confide	L'histoire de ce roi
Of that king who died	Mort de n'avoir pas
From not meeting you	Pu te rencontrer
Don’t leave me now	Ne me quitte pas (4 fois)
Don’t leave me now	
Don’t leave me now	

And often it’s true	On a vu souvent
That flames spill anew	Rejaillir le feu
From ancient volcanoes	De l'ancien volcan
We thought were too old	Qu'on croyait trop vieux
When all’s said and done	Il est paraît-il
Scorched fields of defeat	Des terres brûlées
Could give us more wheat	Donnant plus de blé
Than the fine April sun	Qu'un meilleur avril
And when evening is nigh	Et quand vient le soir
With flames overhead	Pour qu'un ciel flamboie
The black and the red	Le rouge et le noir
Aren’t they joined in the sky?	Ne s'épousent-ils pas
Don’t leave me now	Ne me quitte pas (4 fois)
Don’t leave me now	
Don’t leave me now	

Don’t leave me now
I will cry no more
I will talk no more
Hide myself somehow
And I’ll see your smile
And I’ll see you dance
And I’ll hear you sing
Hear your laughter ring
Let me be for you
The shadow of your shadow
The shadow of your hand
The dog at your command
Don’t leave me now
Don’t leave me now
Don’t leave me now

Ne me quitte pas
Je ne vais plus pleurer
Je ne vais plus parler
Je me cacherai là
À te regarder
Danser et sourire
Et à t'écouter
Chanter et puis rire
Laisse-moi devenir
L'ombre de ton ombre
L'ombre de ta main
L'ombre de ton chien
Ne me quitte pas (4 fois)

Notes: Alec and I had a very wide and varied musical taste. “Ne me quitte pas” by Jaques Brel is one of my all time favourite songs, and it played that particular morning, and I decided to do a post for Alec, in the hope that one day he would read it. I cannot remember where I found the translation.

In hindsight, he did not leave me then. He was doing his damnedest to get better. But he has left me now.

Out of breath – heidil

4:10PM, Monday, 03 Mar, 2008

Hello

Sjoe, I am out of breath after dancing several jigs around the rosemary bush!!!

Pieter has just phoned and asked me to update all of you on Alec's progress! And thank you all once again from the bottom of their hearts for all your thoughts and prayers!

Alec is doing fine; in fact more than fine, he is doing darn well brilliantly! Pieter tells me that this afternoon’s visit was filled with tears – tears of joy. He, Pieter has tried hard not to cry or break down in front of Alec, but today was just too much, and he did! Alec is trying so hard to make coherent sentences, and he is succeeding! As long as he talks very slowly, he is able to make himself understood, and this is what has Pieter so happy!

It does, however sound like Alec will not be discharged on Wednesday as we had hoped, because the IV treatment, according to the nurse, is only the first phase in this very intensive treatment that Alec is getting. She was unable to tell Pieter what the next phase would be, so he will be leaving a note for the specialist tonight asking him what the next step is and what we can expect.

Alec is eager to go home – he must be so tired of lying in bed and doing nothing, but he does understand that this is all to help him get better, so he is being very brave about it.

So everyone, please keep those thoughts alive, the candles burning and the prayers coming because we want Alec to go home just as much as he wants to, and I believe that if we keep sending out these positive thoughts it will happen so much quicker!

I think this piece of prose is very apt under the circumstances, and is something we all need to take to heart every once in a while!

Next time you hear from me, I'll be blogging from Pieter's lap (figuratively not literally) if Jess allows me, that is!!!

Don't Quit

When things go wrong, as they sometimes will,
When the road you're trudging seems all up hill,
When the funds are low and the debts are high,
And you want to smile, but you have to sigh,
When care is pressing you down a bit,
Rest if you must, but don't you quit.

Life is queer with its twists and turns,
As everyone of us sometimes learns,
And many a failure turns about
When he might have won had he stuck it out;
Don't give up, though the pace seems slow -
You might succeed with another blow.

Often the goal is nearer than
It seems to a faint and faltering man,
Often the struggler has given up
When he might have captured the victor's cup.
And he learned too late, when the night slipped down,
How close he was to the golden crown.

Success is failure turned inside out -
The silver tint of the clouds of doubt -
And you never can tell how close you are,
It may be near when it seems afar;
So stick to the fight when you're hardest hit -
It's when things seem worst that you mustn't quit.

(Unknown)

Notes: My visit that afternoon went very well. I remember being excited because when Alec tried to slow down his speech he could speak clearly and more audibly. Alec was in good spirits because of this and enjoyed the food I took along. We discovered a patch to the back of the ward (outside) where we could sit in the sun and have a cigarette without too many eyes staring at us.

That evening I went to visit again only to find Alec a bit tearful. In hindsight I think it was just frustration and fear. Fear of what was happening to him. The shower went well but with dinner I noticed the chipmunk trait again – he would stuff his mouth and not swallow. Again I shrugged it off as just the excitement of eating proper food and not hospital food. And all the while he asked questions – “What If?” questions. Some of the questions I could not answer, because I just did not know. But some of them I could. If he asked: “Will I be able to work again?”, I’d reassure him that he did not have to worry about work, I’d look after him. I’d take care of him. All he had to do was focus on getting better.

Tuesday morning update

8:47AM, Tuesday, 04 Mar, 2008

Morning all

So Heidi shared the “good” news yesterday afternoon. If Alec really concentrates and slows down his thinking and then tries to speak slowly, he can. So it is baby steps.

However … I am no psychologist nor doctor nor neurologist, *but* this is what I see. I think now that the medication is starting to work, Alec realises what is happening or what has happened, and this I think has created a delayed shock. Why? Last night there were a lot of questions. What if I am never able to fully recover, what if I can never speak properly again? And no matter *how* you reassure him that things are getting better, he just cries in frustration because it is not right *now*. I even tried basic inhaling/exhaling techniques with him but it did not work – he was just too worked up. Also I find that he has periods where he is better (yesterday afternoon) and periods where he is immensely frustrated (last night).

This morning they just gave me the standard “He is up and about” message.

Alec has not responded negatively to the fourth day’s therapy and today is the last day of his intravenous drip treatment. I hope (please note – *hope*) to speak to his specialist today. I know he is going for a series of blood tests today, so we’ll see from the results tomorrow how he fared with the intravenous drip treatment. I also suspect that he will go for an MRI scan again soon to see if they were able to stop the lesions to form on his brain, whether it has improved or whether it has deteriorated. I pray for an improvement because it will confirm the second diagnosis.

Any one out there with any advice on how I can assist Alec with his speech will be greatly appreciated.

Then – *thank you* for all the candles that were lit for Alec and me. I have vowed to light a candle for Alec everyday until he is better. Should you wish to light a candle or relight another candle, please go to. Light a Candle for Alec.

Me? I am fine. I am exhausted, yes, but I do cope – thankfully. The ulcer seems to be something of the past. Emotionally I do have my moments, but I don’t fight it when I am alone. I also have my own set of “what if?” questions, but those will get answered by God and God alone. I realise that and tend not to dwell on it.

Wishing all of you a terrific Tuesday! And remember – tell your loved ones that you love them.

Love
Pieter

PS: HeidiL if you see this message still this morning – please have a safe trip! See you on the morrow!

Notes: During the time that Alec was in hospital, I developed an ulcer. It was as a result of not eating properly and being worried about Alec. After two nights of treating it myself with a tried and trusted home remedy, Zambuk, I could report that morning that the ulcer had gone.

Of importance here as well, was that I was brought under the impression that Alec would have had to go for a second MRI scan to establish whether the lesions have spread or not. In hindsight, one probably would not have been able to notice in such a short period of time, or perhaps I misunderstood what was said; perhaps they meant after a couple of months. However, Alec never went for a MRI scan again. And the nursing staff and doctors could have taken more pain in explaining things properly – they could have involved me more in Alec's diagnosis and care.

All I knew about PML at that stage was what I have learnt on the Internet. There was no Doctor / Patient / Caregiver interaction at all, despite me leaving notes for them to contact me. One never was certain when they were doing their rounds. It could be at any time. And this is something I found ONLY in the Public Health sector.

Along with Heidi, I had to take initiative to find ways to help Alec once he got discharged from hospital – I received no empowerment from the hospital at all. I had to request help / advice on the Internet on how best to assist Alec.

Tuesday afternoon feedback

4:55PM, Tuesday, 04 Mar, 2008

Hi there

Sad sad sad. I feel like crying with Alec.

When I arrived this afternoon he looked so radiant, so well, so happy, I even remarked about it. Took him some macaroni and cheese and he tried to tell me something like it's not necessary. We went outside nonetheless and he was like a happy child about to get a gift.

Eventually I could get it out of him that the doctor said he can go home today. I immediately went inside to check on this and they said no, they are still waiting on results. And I had to break the news to him.

Alec was so upset, so disappointed. *But* the good news is, I think, that discharge is imminent. I am sure it will be tomorrow as his progress is really well.

Other good news. I took him a little book and a pen so that he can try and write. He couldn't a week ago. Happy child showed me the book proudly...... He wrote one word twice – his name! But in stead of Alec, he wrote Alex. But that's fine – he can write!

And it does not stop there!! I wrote underneath his name "Well done""and asked him to read it back to me. And though it took him a few seconds for the words to register, he read it back to me. And when I wrote "I love you" and asked him what stood there, he got this sheepish, shy smile and said "I love you too".

Now that I am home – the tears are *streaking* down my face. But it is tears of joy. And perhaps a bit of tired tears too, I don't know. But I am *happy*!!! Not sad.

Tell your loved ones you love them please. Don't take them for granted. I did not take Alec for granted, but I nearly lost him. And I realise, that in the short time we are together, I have not *nearly* told him enough how much I love him.

You guys and girls keep well. And *please* continue the prayers, as Alec and I do.

Love
Pieter

Notes: When I arrived at hospital that afternoon Alec really looked radiant – all smiles. I took him some macaroni and cheese, which initially he did not want to eat. He kept on telling me "Home, Home". So I asked him if he was being discharged and his face lit up as he said "y-e-e-e-s". As I was daft for taking so long to realise what he was trying to tell me. I can actually still hear that yes in my mind.

So I set off in search of the nurse in charge of the ward with Alec in tow. I asked her if Alec was getting discharged and she explained to me why he could not be discharged that day. This upset Alec immensely, and he tried his utmost best to convince her that the doctor said he could go, but she just could not understand Alec. It took some effort to calm Alec down and explain to him that the doctor probably meant the following day. But Alec was adamant that the doctor had said he could go home that day. In hindsight, Alec probably thought that I did not want him home.

Some days before, I had taken a little book and a pen to Alec so that perhaps he could try his hand at writing again. His attempt gave me immense hope. I wrote underneath his writing "Well done" and asked him to read it back to me, which he did with only some hesitation. But when I wrote "I Love You" and asked him to read it back to me, was perhaps the time that I had the most hope, because he got that sheepish grin on his face and said: "I love you too". To me this little act – him writing, reading things back normally, and understanding what was written – proved unequivocally that he was on the mend.

During these last two days in hospital, Alec became very active – walking around, walking with me. I told Alec that the more active he was the higher his CD4 count would become. So he followed my advice. I also noticed that he recognised and pointed stuff out to me – cats, familiar stellar constellations. All little signs I grasped at then, because they gave me hope.

Alec was also very excited about Heidi's visit, but also concerned – what would Heidi think of him. Alec was a very immaculate person and I could imagine that he would not want Heidi to see him in his pyjamas. So that night I took him his favourite pair of jeans and a nice shirt, so that he could have that to wear during our visit the following day. I can recall that I have resorted to accept that he would not be discharged the following day, but I did not say that to him.

Wednesday morning update

8:40AM, Wednesday, 05 Mar, 2008

Morning All

I didn't have too good a night. First of all, Jessy was very restless and just could not get settled. Secondly, I suspect because of Alec's disappointment yesterday afternoon, I have been very tense and that took its toll on my "ulcer" – under-achiever that it is, it kept me up for a bit. Eventually I drifted off to sleep some time after 01:00.

My visit to Alec last night was less fruitful than yesterday afternoon, but I expected that. The shower went okay, but I could see Alec was still disappointed about not being able to go home. So I explained to him I'd much rather have him there and get better and (until) we are sure that he is better, than him coming home and compromising his health. With the right amount of "I love you's" and "because I love you's" it seemed to have calmed him down. He is up and about a lot, walking the corridors and he starts noticing things like the Southern Cross, pointing it out to me etc. So, all in all, good signs.

I have also accepted that this whole thing is going to take some time still before he is fully recovered, *but* we are *well* on the way.

Both yesterday afternoon and evening Alec was very concerned about what Heidi would think of him seeing him in his pyjamas. And no amount of comforting from me or Heidi's assurances that she would not mind could calm him down. But at the same time he is very excited about her coming to visit.

Now about Heidi – is this woman a saint or what? Coming all the way from East London to Quiet Fountain to visit Alec. For a day. I phoned her this morning to find out how she is doing and what time her bus to Klerksdorp leaves. So I asked her to sms me when they go through Potchefstroom so that I can co-ordinate my departure time from home so that I can be in time to pick her up. The bus stops 5 minutes from where I stay – at 12:00. You know what she says to me? No worry, she'll wait for me till it is time to go and visit Alec – which is 14:30. She must think I am daft – how can I do that?

Now for some questions answered:

Kingfisher 2 – yes, he did eat his M&C. Eventually.
Cat Woman – I'd be lying if I say I am not exhausted and that this whole thing is not taking its toll on me. However, now more than ever I have to remain strong for Alec – *especially* when he gets impatient.
Lyndatjie – I wish I had left to pick him up, but alas. I have just phoned the hospital. His condition is still the same as yesterday and they are still waiting on the doctor to do his rounds before we will know whether he will be discharged or not. But he is fine this morning, they say.

So all of you have a wicked Wednesday and pray that Alec gets discharged today. Please.

And remember: Say after me ...

Love
Pieter

Notes: I remember being a bit anxious about Heidi’s visit. We spoke over the phone daily by now, but we had not met yet. Dad was very excited about Heidi’s visit too. For him, the fact that Heidi, a complete stranger to our family, was coming to visit for just one day, told him a lot about her character.

Nearly midday

11:08AM, Wednesday, 05 Mar, 2008

Hi All

Heidi is nearly halfway between JNB and Klerksdorp and I am nearly getting ready to go and meet her.

Still no word from the hospital, but they are notorious for it. We'll see this afternoon what the outcome is.

In the meantime, since we are dealing with hospitals and doctors and stuff, a joke Sussa emailed me this morning. Dankie Sussa dat jy my laat lag het – I needed that. (Translated: Thank you Sis that you made me laugh – I needed that).

Take care

Pieter

Notes: For some reason, the joke my sister sent me got deleted and I cannot remember what it was other than a Zapiro cartoon, I think, aimed at Dr M. (Manto Tshabalala Msimang).

I left shortly after this post was posted, to go and meet Heidi off the bus. I recall that I needed to stop off at Fruit and Veg City to buy mushrooms, but decided that I would first wait for the bus to arrive, and then Heidi and I could go to Fruit and Veg together. As I turned into Flamwood Walk, the area where the buses stop, my Dad phoned me on my cell phone to say that the hospital had just phoned and said that I could go and fetch Alec. I was over the moon with excitement.

As the bus pulled in, I got out of the car and could not wait to share the news with Heidi. As I greeted Heidi and gave her a hug, I told her that Alec was being discharged from hospital. Heidi jumped up and down for joy. We popped over to Fruit and Veg in a rush and then went to the hospital to fetch Alec. Disappointment, though – Security at the main gate phoned Alec's ward who said that we could only fetch him later that afternoon. They wouldn't even allow us in to see Alec for 5 minutes. So we had to return home.

Midday feedback

2:09PM, Wednesday, 05 Mar, 2008

Hi there all

Just to say that Heidi has arrived safely!! And *what* a *fabulous* person she is!! It feels as if we have known each other for ages!!! She is quickly having a shower to freshen up after her long trip!

Now my story: on my way to fetch Heidi, just as I took the turn into the parking lot, Dad phoned me. The hospital had *just* phoned to say we can come and fetch Alec. So Heidi and I left immediately to go and fetch him. Arrived at the hospital, no, we can only get him at 15:00. He does not have his meds yet. And there is no way we can get into the ward before 3.

Ag well – does not matter. My hubby is coming home today and at 14:30 Heidi and I are going to fetch him.

WELCOME HOME ALEC !!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!!

Guys, girls, friends. You do not know me, and I do not know you personally, but a *huge thank you* for carrying us through this time!!! *But please* continue your prayers for Alec's *full* recovery – soon.

And remember – tell your loved ones that you love them.

I will not be blogging for the rest of the day – I want to make most of Alec's home coming and Heidi's visit. So I will update you again tomorrow (perhaps later – but no promises)

Love
Pieter

PS: On the menu tonight:

Chicken Pie
Roast Potatoes
Sweetcorn fresh from the garden,
Beetroot salad and
a Green Salad

Notes: As I write this I am very emotional. The 5th of March 2008 has a special significance in my heart. Heidi and I left for the hospital around 14:30. The Security Guard recognized us from earlier and waved us through. We parked very close to Alec's ward. When we got there, Alec was actually waiting in the corridor for us, so excited, so happy. He could go home. But alas, we still had to wait for his medication (ARV's). We waited for about half an hour. As we got into the car, I said: "Finally!" and Alec (clapping his hands) said with a beatific smile: "Yippee!"

I will never be able to forget that "Yippee" and I will never be able to hold back the tears when I hear it in my mind.

Upon our arrival at home, the dogs nearly ate Alec up out of joy. We put his belongings down in the room and I immediately went to show Alec the baby tortoises outside. He looked at them in amazement and just said: "Ag jinne" (Translated: My goodness or Ah Sweet). Those are two words I will also never be able to forget, and I cry as well when I hear them in my mind.

I recall showing Alec the post I did for him. I was sitting in my highback, and he stood behind me, with his hand on my shoulder. When he read the words "Welcome Home Alec!!!!!!", he bent down to give me a kiss.

Because Heidi was there for only one day, I invited Annemarie and Simmi to come and visit, as well as my sister. A good time was had by all.

But it was also on that day that I began to understand the extent of the damage to Alec's brain. After watching some DVD of just a few months earlier, I think the reality sank in for all of us – Alec included, as he started to cry inconsolably. And I dared not cry, because I had to be strong for him.

Heidi brought along a myriad of toys, colouring books and puzzles. All were aimed at assisting Alec to restore his abilities. When Heidi gave him the toys, Alec started to cry – not a despairing cry, but a grateful one. A cry that showed Alec understood that he was loved – even by a complete stranger. Heidi also brought Alec some biltong and dry wors. Alec never ate any of it ...

But all that mattered, especially that day, was that Alec was home and back in our bed. Both of us slept soundly that night – holding on to each other.

Thursday Post-Heidi

1:21PM, Thursday, 06 Mar, 2008

Hi there all

If ever I have seen an angel from heaven, that is Heidi. I agree with Rose's comment yesterday, someone should design her a saint badge – if only I knew how. We had such an awesome time and Alec soooo enjoyed her company.

Honesty first. At the moment Alec is a child. A big child. One that has to learn everything from scratch. He has to learn to read, to write, to speak. Although he has all his cognitives stable and positive, he has suffered damage that now needs repairing. So Heidi brought Alec some gifts:

A book where he has to follow the dots and which teaches you to write again. A puzzle (he was very excited when he saw that), some balsa wood puzzles he has to put together – easy ones to begin with and then progressing to more difficult ones. She brought him some playing cards with the big five on them, a domino set, where each number has a different colour to it, a book where Alec has to follow the dots to complete the picture. *All* of this from the bottom of her heart just to help someone she only met yesterday!! God bless her soul!!!

Alec was excited to get out of hospital and of course I had a full house with Sussa coming to visit, Anne and Simmi and of course Heidi. And the dogs did not leave Alec alone for one minute.

Dinner was a huge success and after packing the dishwasher Heids, Alec and I proceeded to watch our bungee DVD's as well as the Zambia photo's. It was whilst watching the bungee DVD's I actually saw *how* much damage was done to Alec's brain

That said – I remain confident that Alec will restore his capacity soon. In fact, I believe.

This morning was very sad though when we saw Heidi off at the bus stop and Alec cried a lot. Understandably he is exhausted now and catching a bit of shut eye, allowing me to work a bit, before we can start using the tools Heidi brought us.

I can however not say what I feel at this stage. I can't say how I feel. It is something between despair and hope, a see-saw feeling. The one moment up and the other moment down. It struck me this morning when Alec came into the office asking me to help him shave.

Something I take for granted, and he can't do it. But God knows, we will get through this.

Again – our heartfelt thanks for every single one thinking of us. I pick up there are a lot of people reading, but words fail them. Every day there are new comments from new people who have never visited my blog before, saying just that. Thank you too, for keeping us in your thoughts.

I shall update you later again. In the meantime, remember to tell your loved ones that you love them. Life is short. Very short indeed.

And Heidi, I know you will only read this day after tomorrow, but you have a *very* special place in our hearts. You are truly a remarkable woman. We love you.

Pieter

Notes: This Thursday was a sad day for us, as Heidi had to go back to East London. Heidi and I were in my office, having coffee, when Alec came in to ask me to help him shave. This was something I started doing for him every so often for the rest of his life. It was also the last morning that he showered alone, because there was a little mishap in the bathroom – somehow he stood on the drainage hole whilst the shower was fully opened, which caused the water to dam up and overflow. So it was decided that I would shower with him to prevent this from happening again. Our showers together became a very special time for me, and till today, when I wash my hair, it actually feels as if Alec is washing my hair, or me his.

Dad called us all into the lounge so that he could read something from the Bible (I cannot remember what he read but it could have been from Ecclesiastes) and said a prayer before Heidi left. Alec, I and Martie went to see Heidi off. Martie had some errands in Klerksdorp that day. We waited quite some time for Heidi's bus to arrive and Alec just stared out in front of him. He was very emotional about Heidi having to leave. As we said goodbye, all three of us were crying.

A special post from Jessy

2:37PM, Thursday, 06 Mar, 2008

Dear blog humans

I feel *soooo* uncomfortable, I just can’t get myself settled. If I knew from the beginning what I have let myself in for, I would have chased Milo away a *long* time ago. At night it is under the duvet, then on top of the duvet, then under, then on top. During the day it is on Daddy P's lap, then off Daddy P's lap. Do you humans also suffer such a lot when you are pregnant?

At *last* I got to meet Aunty Heidi. Normally I growl at strangers when they get too close to either Daddy P or Daddy A, but I liked aunty Heidi instantly. Why should I not like her? After all, she is the one that gives Milo and myself such a lot of e-tummy rubs and e-billies. So it felt as if I knew her forever. It was however very nice to get a real tummy rub from her *and*, listen to this, she even bought Milo and myself a bag of raw-hide bones each. What an angel she is.

Milo and I are sure glad Daddy A is back home and both of us now keep a very watchful eye on him. We don't want him to go away again for such a long time. And Daddy P often catches us on the bed with Daddy A. But we don't care – we're there to look after him. And although Daddy A talks strange at the moment, we know that he loves us now more than ever.

But I also have to look after Daddy P – he looks very tired to me, so I try and give him some positive energy by just sitting on his lap and staring into his eyes with my big brown eyes and every so often giving him a lick on the chin.

We sure hope Aunty Heidi comes to visit again soon.

But let me leave Daddy P to work some.

Love
Jessy

Notes: Both dogs were happy that Alec was home. Though we wanted Jessy to get used to staying on the stoep until after her litter was weaned, those past two days we allowed the dogs to sit on our bed with Alec. Alec would spend some time with me in the office, and then he would go to the room to rest or watch a bit of TV. And every so often, when he was awake, I would take him for a stroll in the garden, with our arms around each other, or hand in hand.

A letter to Alec

7:06PM, Thursday, 06 Mar, 2008

My Darling Alec

I look at you and I cry. Not so that you can hear the sobs. Not so that you can see the tears. Inwardly. Outwardly you see a smile. And I see you smile back. And I realise you trust me not to crack up in front of you.

And you are right to trust me. I will not forsake you. But I also have my own fears Alec. I am scared by what I see. In five weeks time you have reduced to a big child. A happy child, but a big child. And I will look at you and wonder. Wonder what is going on inside your mind. If you are also scared. If you are also afraid.

You have to be, because often I have to comfort you. Often I have to hold you when you cry out of sheer frustration.

Sometimes I wonder if you understand what is happening to you. But then I watch your reaction to the characters in your favourite soapie. And I realise you *have* to understand. And it gives me hope, darling, it gives me hope.

Alec, it may take a while for you to get better. But please know this. I will not forsake you. I will not give up hope, even if sometimes, I feel hopeless. God knows – we will get through this. I just hope it can be soon. But God will decide about that.

Just know, that I love you. Still.

Love
Pieter

PS: Some people say you are lucky to have a man like me. They're wrong. I am lucky to have a man like you!

Notes: I observed Alec lying next to me on the bed as we watched 7de Laan, our favourite soapie. From the time Alec moved in with me, 7de Laan time had become our "us" time. I wondered what was going through his mind and whether he understood. His reaction to one of his least favourite characters in the show proved to me that he did.

I always tried not to cry in front of Alec, not to show my fear in front of Alec, for fear it would upset him. So outwardly I smiled at him, but inwardly my heart was bursting; inwardly I was crying – I was actually shit scared. And sometimes, when it became too much, I would go outside and cry there.

In a lot of the comments we received on Jessysjungle, people told me how lucky Alec was to have me by his side. I didn't like it when people made those comments, it made me feel uncomfortable. I still don't like it – I don't take easily to comlpiments.

Friday morning update

8:25AM, Friday, 07 Mar, 2008

Good morning all

Glad to report both of us had a very good night. And when I woke up this morning at 05:00 and saw Alec next to me, breathing restfully, I shot up a prayer of thanks to God for him still being there, as both of us forgot to pray last night. Well, not actually forgot, but the intention was to pray after Strictly Come Dancing's second half, but both of us fell asleep before the results were out.

I had a shower this morning and after the shower I went into the room to find Alec crying. So I comforted him, and asked him why he was sad. So he pointed to the balloon Heidi has bought him. A red one, with the words "Get Well Soon!!" on it. How could I not cry with him, on this one? If I could switch places with him – I would have done that in the blink of an eye. It is so unfair – I have led a privileged life – varsity education, parents that loved me, a "good" life. He, he grew up with his grand parents, his parents have rejected him some twenty odd years ago, never had a stable family life until June 2007, had to fight all his life for what he wanted. And now this.

Heidi phoned early this morning to say she had arrived safely home. Lyndatjie gave me an excellent idea, and I will contact our favourite crustacean with a task – a badge for Heidi!.

I have loads to do this morning – apart from tending to Alec – I want to get him cracking on the Big Five puzzle Heidi brought. But apart from that I have two group quotes that await my *urgent* attention, and I can do with the dough right now.

Thank you once again for all your positive thoughts and comments and prayers.

And remember – *love* your loved ones. Don't *tell* them you love them. *Love* them.

Take care
Pieter

PS: I am going to try something with Alec today. Even if I can just get him to type the word *dankie* (thank you), for you guys, I would have accomplished my mission for today!

Notes: I remember waking up that morning and feeling guilty for not praying the previous night. As Alec was sleeping soundly and his breathing was regular, I just lay there next to him immersed in my own thoughts:
"Would he ever get better?"
"Would it be wrong if I had sex with him?"
"Would we ever have sex again?"
"Why is this happening to me?"
"Why am I not the one who is sick?"
"Why must it be Alec?"
"Would a God of Love destroy what there was between us?"
"Is there a God of Love?"
And then I would feel guilty for thinking it.

"What did he do to deserve this?"

Alec had had a very unhappy childhood and a rather tumultuous life, that only gained stability when he returned to Potchefstroom in 2006.

I remember, as we lay there, I put my hand on his head and started praying to God, thanking Him that Alec was still there, begging Him to make Alec better.

Seeing Alec cry about the balloon was heart wrenching and I could not help but cry with him – whilst comforting him, reassuring him that all would be okay. I wanted Alec to get cracking with the therapeutic toys that Heidi had brought.

Boys and their toys

9:51AM, Friday, 07 Mar, 2008

Hiya

Boys and their toys. Ai. Alec has just had breakfast and I asked him what he wants to do today, hoping he would select the puzzle. Okay, I gently nudged him in that direction. So I cleared space in the office for him to work, but it was not enough. So I asked him whether he perhaps want to do something else. And no. Mister is adamant – a puzzle is what he wants to build today.

I also noticed that, so far, his speech has been consistent – clear audible sentences, without the stuttering, but still sounding like a retarded person's speech (I *hate* that word, and use it only to describe his speech – please *do not* get me wrong). Which is good. It's positive. Satan is just out to get me to make me notice the things that are hampering, instead of noticing the improvements. And in the end, I suppose it is only human.

So, Happy Child is happily building a puzzle. And I love him for that. He *is* trying. Alec, *I love you sooooo* much! And I won't interfere with his puzzle building – *only* when he asks me for help, will I help him!

Again – *thank you* (you'll find that I will never be able to say thank you enough for your support. For being there for me (and Alec) in this difficult time.

Love
Pieter

Notes: I admit – I had a lot on my plate at the time, but I made the decision that Alec came first and work second. Alec and his recovery were more important than any money in the world to me.

I took great delight in seeing Alec getting excited about the smallest accomplishment. I tried to praise him, encourage him. What was heart wrenching though was to see how he struggled with the smallest things that I took for granted. I had to show him first how to build his puzzle, and then had to dismantle it so that he could start from scratch. I was, however, encouraged to see that he grasped the concepts and duplicated them, and that continued to give me hope.

A thank you from Jessy

12:51PM, Friday, 07 Mar, 2008

Dear Blog Humans

Big was my and Daddy P's surprise when we got an email telling us we got third in the Blog Off. We did not even realise we were in the running.

Now as you know, I am pregnant, so I may not drink. And besides, doggies are not supposed to drink in any case. So I will give my prize to Daddy P and Daddy A (and hopefully they will give me some biltong and tummy rubs in exchange).

And thank you for voting for us!!

Love
(a *very* pregnant) Jessy JR

Notes: Blogs24.com in association with Perdeberg Wines ran a competition, where each week you had to “clink” on your favourite blogs. The most “clinked” blog would win 12 bottles, second-most 6 bottles and third-most 3 bottles of wine. This week Jessysjungle won third place and therefore 3 bottles of wine. Alec was so chuffed with this. And of course Jessy had to say thank you to her audience. Alec never did get around to sharing that wine with me, though.

Friday afternoon feedback

2:03PM, Friday, 07 Mar, 2008

Hi there friends

Hmmm. I see Jess has won us some wine. *Thank you* Jessy. Promise I'll give you some biltong.

Okay. So the meds have put Alec out most of the morning and when he returned to continue his puzzle we realised that, no matter *how* hard we try for space in my office, it just is not going to work here. So we have opted for rather building a model plane (very basic, but it helps) instead.

I have asked Happy Child if he wants to try his hand at typing, so here goes: (Over to Alec):

dankie

(Back to Pieter)

Ok, so (what) I did was to write the word Dankie on a piece of paper and had him find the correct keys on the laptop. Which he did. Took him about 4 minutes, but still – he was able to spot right from wrong and once he discovered that he managed to type the word, he was as excited as a child.

And on this rather positive note – we will check in again into blog land a bit later this afternoon.

Take care

Pieter

Notes: I so remember this day; when Alec typed the word "dankie" (thank you) onto my blogpost, and once he saw that he had got it right, he jumped up and down with excitement and a huge smile on his face. I was overjoyed to see him so positive. He hugged and kissed me with such enthusiasm.

I cannot remember all his medicine's names. I know he had to take 5 different kinds of anti-retrovirals, one of which he had to take 12 pills of at one time. These were evidently very bitter. I really felt for the man. To see his face contorting when those pills went into his mouth, heavens, it was hell. Why on earth they did not give him fewer pills with a higher active ingredient content, was beyond me. They did not have in stock, was all they said when we asked them.

One last post for the day

4:07PM, Friday, 07 Mar, 2008

Hi there

What a hectic day it has been. In amongst tending to Alec I had to do some work as well. And am happy to say I am nearly on track again.

Alec managed to build all three his "model planes" and he is so happy and chuffed with himself. It's these styrofoam planes where you just have to insert the wing and the tail and put on the propeller. We played with it in the garden a bit as well.

Tonight we are going to play a bit of dominoes.

Thanks for carrying us this week in your thoughts, prayers and for all the well wishes. We are still overwhelmed. I have decided to make Alec a scrapbook with all the posts and stuff and one day (soon) we can look at the horrible period in our life that brought us so much closer.

Love
Pieter

Notes: All in all Friday the 7th was a good day. Alec managed to build his three "model" planes and we played with them in the back garden, by throwing them to each other. Alec had a radiant smile as he saw them glide through the air and would run to pick it up where it landed, just like a child would.. He helped me a bit with the food preparations in the kitchen. Although he mostly just stood there keeping me company, being close by. It is the company that was most important to me.

After dinner we retired to our room to watch 7de Laan and the final episode of Noot vir Noot. In the series there was this blind man participating and who had gone through to the finals. Alec recognised him, and was saddened that he did not win. In fact he cried. Alec was like that. For instance, when someone sang beautifully it would have him in tears, or if someone at a disadvantage won a competition, he would cry about it, out of joy.

It was also a night that I felt extremely close to Alec. With him falling asleep while watching a movie, all I could do was pray for his healing, for his recovery while he was sleeping with his head on my chest.

Perhaps this book, is the scrapbook I intended to make?

Saturday morning

8:05AM, Saturday, 08 Mar, 2008

Hi there friends

Yes. Friends. Your support, comments and concerns are those of friends, not enemies, not strangers.

So, feedback time. Last night Alec and I played dominoes. It is one of these sets where each number has a different colour – so it works *both* ways, number co-ordination *and* colour co-ordination. And though we played without rules, Alec did have an *excellent* grasp of both colours and numbers. Not once did I have to correct him. Small little signs. Baby steps.

Thereafter we watched the season finale of *Noot vir Noot* and Alec recognised the blind participant *and* felt upset because he did not win. And then we watched Mission Impossible III. He fell asleep in in my arms about 3/4 way through. It was soooo special. And at that time I just put my hands on his head and prayed and prayed and prayed – without crying.

This morning I woke up and went to make some coffee when I bumped my toe. It is bloody sore. And Alec is now so concerned about the foot. But it is just a minor sprain.

Anne and Simmi are coming for a braai today. Alec is getting his new laptop – his old one went in for repairs and they decided to replace it with a new one. I am glad about this because it will help him immensely, I am sure. Doing familiar things like surfing the web. Might sound dumb, but as Xena said – new neurons need to be built.

HeidiL – Hope your first day back at work is SUPER my friend. Remember, we love you and are so grateful and honoured to have you as a friend. *Amigos para sempre*?

Oh yes – all of a sudden work also starts to look up a bit. Confident that March is going to be a good month.

On that note: -

The dishwasher needs unpacking and repacking
Coffee!!!
Shower and shave and bed need to be made
Breakfast
and only *then* can we build some of the puzzle.
(Yep – Alec needs routine as well)

And then tomorrow we are invited for breakfast at one of my friend's house. A change of scenery will do Alec the world of good.

So my dear friends – have a sumptuous Saturday.

And remember . . . (Now all say after me in a chorus)

Love
Pieter (and Alec)

Notes: Alec was looking forward to this day. We had waited for over 3 weeks for his new laptop to arrive. Alec was the electronics guy in the house. He liked his fancy cell phones and laptops, and he could not wait to get this new one.

While going into the kitchen, I bumped my toe against a doorstop and it was so painful that I actually cried from the pain. Alec kept on saying, “doctor, doctor”, and I had to convince him that it probably was only a sprain or a bruise. In hindsight, I think it was cracked, because it remained painful for quite a few days.

If I was to help Alec fully, I realised he had to have structure to his day. There had to be routine. Such as brushing your teeth, having a shower, making the bed. I realised things cannot happen haphazardly. I tried my best to stick to some form of routine for his benefit.

I wonder

9:17AM, Saturday, 08 Mar, 2008

Hi there

I see a lot of comments praising me for standing by Alec the way I do. And though I appreciate the comments, it also makes me feel a bit awkward. It makes me feel awkward because I feel, no matter what, it is my *duty* to stand by Alec. Because, you too, would have done exactly the same for your life partner – be it husband, wife, boyfriend, girlfriend, same sex partner. Would you not? So then what right have I to claim or receive praise for something that is our God given duty? I know, were the roles reversed, Alec would have done exactly the same for me.

Having said that, though – I do hope that people see that we love exactly the same way heterosexual couples do. Not wanting to make this a gay rights thing *no!* Rather a "Love is universal" kind of thing. There is no difference in love. No distinction. Just the will to do what is the right thing – supporting your best friend – that is all God expects from us. Not to turn against each other. How can I, now that Alec is sick, turn around and say "I don't want you anymore – you're not the person I have met and fell in love with". Now, more than ever, it is my duty to get him back where he once was.

And if *that* is an inspiration to someone, *then* I think God has achieved *His* goal, not me. Because I am a mere humble instrument in *His* hands.

Have a super Saturday, now that my little life lesson is over.

Love
Pieter

Notes: I received a lot of comments on my posts that Alec was lucky to have someone like me by his side, complimenting me on the way in which I was looking after him. To me it comes naturally – if you love someone, really love someone, I believe there is nothing you would not do for that person. Alec was my soulmate, and there was basically nothing I wouldn't not do for him. How can you love someone in health, but not be there for him in sickness? This does not make sense to me. Not at all. Some bloggers pointed out in a comment to me, that not all people are like me, and it baffles me. Until today, it baffles me.

I was so excited to see that Alec was not succumbing to depression. Of his own accord he started helping on the Saturday morning with tasks that needed to be done. To me it showed that he was not going to take what was happening to him lying down – but that he was going to try his utmost best. I was so elated when he went and made me a cup of coffee. HE wanted to do something for ME. That made me feel so special. And that is how we were – we did things for each other.

Saturday noon

12:20PM, Saturday, 08 Mar, 2008

Hiya friends

First of all, thanks for the comments, Lyndatjie DT and Blanket, to my previous post. I suppose I am one of those people that do not take easy to compliments. But Lyndatjie, you said something, which, if you're into Numerology and the Human Pin Code, you would not have realised. I am a 2 which in numerological terms means I am a nurturer...

Alec had quite a morning – we finished the trunk of the elephant with his puzzle, he helped me clean the room out of his own – not me asking him), even attempted making coffee – okay he mixed dessert spoons and table spoons up, and did not boil the kettle, but that is *sooo* unimportant. He wanted to make ME a cup of coffee!!!! That is what is important. And then I clipped his nails for him – they annoyed him. Have to be honest that I have never in my life clipped someone's nails for him or her, and I do hope that he is happy with my manicure attempt. Another thing that I notice on a regular basis is that Alec realises when he is making a mistake and *thankfully* he just shrugs it off and laughs about it. He does not allow it to get him under.

But now he has succumbed to sleep. The meds still hit him for a six. So let him sleep a bit, Anne and Simmi are nearly here and then he will have to be bright-eyed and bushy-tailed. We are having ourselves a little braai for him.

Other matters – Jessy is *really* swelling up now. I have nicknamed her Tieties du Toit – she looks so funny with her 8 nipples standing in 9 different directions. But ever so lovable, and ever so concerned about Alec. And Alec about her. There is a new depth in their relationship.

Sadly though, Jessy and I will *not* blog about one of our close friends anymore – Aunty Fag Hag is scrapped as a character from our plot. I entrusted her with certain information in confidence (as we always do) and two days ago it came back to bite me in the bum and severely distorted as well. It concerned me and Alec (and I suppose Lyndatjie), that is when the *bulldog* in me that came out. You touch Alec and you touch me. Aunty Fag Hag overstepped the boundaries. All forgiven and nearly forgotten, but the trust relationship is severed and I do not see it possible to mend this one.

Well, I hear my four-legged doorbells, which means Anne and Simmi has arrived, and therefore I shall love and leave you.

Now repeat after me ... (aaaahh – so nice to hear)

Love
Jess

Notes: I notice now that I have signed this blogpost as Jess. I cannot think why I did. Perhaps I was tired. About the part where I said Alec realised when he made a mistake – the fact that he could recognise that he made a mistake and then acknowledge it, gave me hope that he was busy recovering. The fact that he just smiled in his own special way about it, and did not let it upset him, showed me that he understood and was not going to let this get him down.

On the 22nd of February, whilst Alec was asleep a bit, I sneaked away to Aunty Fag Hag. I told her that Alec was HIV+ and discussed my fears with her. Presumably she went and told her daughter, who is married to Martie's son, that Alec had Aids, that Alec was going to die and that I most probably was going to die too. Martie brought it to my attention, because her son had phoned her the previous night and told her that his wife had said that Alec was busy dying of Aids and wanted to know if it was true. I felt betrayed by this. I went to great lengths to explain to Aunty Fag Hag, (who was my confidante), the difference between being HIV+ and having Aids. I vowed that night never to speak to her again but kept this little fact to myself and did not share it with Alec, since he was very fond of Aunty Fag Hag. Months later I would learn that it was indeed not Aunty Fag Hag that breached my trust, but Martie herself. She told her son about it and turned the story around and told me, after she spoke to him, that Aunty Fag Hag told him that Alec had Aids .

Alec always enjoyed a braai. In fact we tried to braai at least once, if not twice a week. He was looking forward to Annemarie and Simmi's visit, because they would bring his new laptop along. Alec was so proud of his new laptop. Some months earlier, Milo chewed off some of the keys from his previous laptop, and the company where the laptop was on lease, decided it would be cheaper to replace the laptop than to replace the keys. It was a most joyous day which exhausted Alec immensely. Little did we know that day would be the last time we would braai together as friends. That it would be the last time that Annemarie and Simmi could enjoy the activity Alec enjoyed so much, together.

That evening, while we were having dinner, Alec choked on a piece of meat. I helped Alec to get to the bathroom and assisted him in getting the piece of meat out of his throat. It was evident, from what came out, that Alec was not chewing properly and taking too big a bite. And then he got hiccups. That was the first day that I became concerned about the chipmunk trait – I tried to convince Alec to slow down his eating and eat smaller pieces. I did this in such a patient way, but I could see it really embarrassed Alec. But it was this that started the nagging feeling in my mind, that perhaps Alec's swallowing reflex was affected.

Sunday morning feedback

8:38AM, Sunday, 09 Mar, 2008

Good morning all

Both of us had a good night's rest. I think yesterday might have been a bit exhausting for Alec, but he did so much enjoy it though. He got his new laptop yesterday, so today I want to get him cracking on that and see how he does.

Have to go for breakfast at friends shortly, then lunch at home and then 16:00 two more friends come to visit Alec.

Alec enjoyed his time with Anne and Simmi immensely. A very positive sign emerged unasked yesterday afternoon. For the death of her Anne *still* don't know how to get to Spar from our house and Alec and I went along. Anne asked me *not* to help her, she wanted to see if she can find her own way. *However,* Alec, showed her where to turn left and where to turn right!!!! For you it might not seem like a lot, but for me that is *wow*!!!

Last night he fell asleep with his head on my shoulder. So precious. So I had my hands on his head again and just prayed and prayed and prayed.

As I said, baby steps at a time, baby steps.

Now say after me, one more time . . .

Love
Pieter

Notes: Yes, I was very hopeful when Alec, of his own accord, showed Annemarie where to turn left and where to turn right. To me it was such a positive sign.

We were scheduled to have breakfast at friends of ours, Peter and Magda. We decided to go to them because I felt it would be good for Alec to have a change of scenery. Alec looked chirpy, forever smiling, whilst we were there. After breakfast we came home so that I could prepare lunch. We needed to be finished with lunch by 16:00, because two other friends of ours were coming over to visit Alec. I made our Sunday usual – roast chicken, rice, vegetables. Alec choked on his food again, and again I had to insert my index finger in his mouth to get the excess out. Again he had bitten off too big a piece of chicken. And again he got the hiccups. I made the decision that perhaps Alec and I should eat in our room from then on, that I would start cutting his meat for him in smaller than bite-size pieces – to spare him the embarrassment.

Thankfully though, the two friends did not arrive, as Alec was feeling tired.

Monday morning

8:15AM, Monday, 10 Mar, 2008

Hi there all

Another day, another week.

Alec and I had a good night again. Ever so thankful that we are saved for each other, yet another day. The brekkie *(sic)* appointment went very well yesterday morning and he enjoyed it. Lunch went equally well and the friends that were supposed to rock up at 16:00 never pitched, but I am grateful for that – we needed the time for ourselves.

This morning Alec woke up and immediately went for his laptop. Which is a good sign. He is showing interest.

I read Lyndatjie's post this morning about her god-child being raped and fighting for her life now. She also went on to explain why she carries a gun. I am anti-firearms BUT I understand why some people feel the need to carry one. And I understand why she carries one too. To me, it is a matter of if you can use it to protect yourself, why not. I am just sad that this beautiful country of ours has come to this, where people live in fear, and every effort has to be made to secure yourself and your loved ones. Yet, I will not leave, because this is my homeland. Lyndatjie, you and your family will be in our thoughts and we wish your god-child a speedy recovery.

So, let me start my day by doing some work. I believe it will be an excellent week.

Again, thank you for continuing keeping Alec and myself in your thoughts and prayers. And remember, *love* your loved ones. Life is short.

Love
Pieter

Notes: Alec was very excited to start working on his laptop that day. We did not get around to it the previous day with all the events.

I was really saddened to learn about a fellow blogger's, who blogs under the pen name Lyndatjie (Remote Control Thingy), plight. The news had visibly upset Alec as well. It was Lyndatjie that started a whole prayer chain that stretched from Cape Town into Johannesburg.

Then an email came in for me from another blogger, whom we fondly refer to as the blog crustacean, 1Largeprawn …

A badge for HeidiL

10:14AM, Monday, 10 Mar, 2008

Hi there all
Pieter here, hi-jacking HeidiL's and Daddy A's blogs for a second or two. Please note that the posts on HeidiL's, Daddy A's and my blog will be exactly the same.
To show my and Alec's appreciation for HeidiL, and following suggestions by other bloggers that Heidi deserves an Angel badge, I

have commissioned our favourite Crustacean to design a badge for HeidiL's and our blogs. Though Heidi, to us, is an Angel in disguise, and though I sometimes refer to her as a saint, I took cognisance of the fact that she feels highly embarrassed when reference is made to that. Which made compiling the badge very easy – a combination of Alec's, Heidi's and my avatars. Combined with the words "Amigos Para Siempre" – which means friends for life.

Heidi, this is just a very small gesture of our appreciation for what you have done for Alec and me! What you have done was beyond the call of friendship, and it will forever be engrained in our hearts.

1 Large Prawn – THANK YOU for a sterling job. I really appreciate.

Love
Pieter

Notes: Following Heidi's selfless act of coming through from East London, all the way, for just one day, and then all the gifts she brought Alec, it was suggested that a badge be created for Heidi. Heidi feels very awkward to be referred to as an angel, so I decided against an angel badge. I asked 1Largeprawn if he would mind creating a badge that contained my, Alec and Heidi's avatars and the words "Amigos para Siempre" (Friends for Life). The badge arrived that morning and I decided to place it onto my, Alec and Heidi's blogs.

Alec cried when he saw the badge, but they were tears of gratitude.

Perhaps today is a not so bright day

12:35PM, Monday, 10 Mar, 2008

Hi there

Although Alec has had a good night and took to his laptop immediately, I note that he is very withdrawn today. Introspective if I could call it that. And today he can’t remember my name, his name or any of the dog's names.

Which of course unleashes all kinds of negative thoughts in my mind – am I doing enough, am I doing too little, am I too hard with him, am I impatient, what if he doesn't make it, what if the damage is permanent, what would I do if I lose him?

As positive (as) I try to be, as negative I can become and I think it is only human. But how does one get rid of all these nagging little devils?

I sincerely hope that when Alec wakes up in half an hour's time he feels on top of the world again.

Pieter

Notes: Alec was so eager to start on his laptop. I helped him to set it up and then handed it to him. After about 10 minutes I took my eyes off my work and looked around, only to see Alec staring at the screen. He could not get into any programmes at all. He could not use the computer. I tried to encourage him a bit to try again, told him not to give up. A little bit later when he started crying inconsolably saying, “kan nie, kan nie, kan nie” (Can’t, can’t, can’t), I told him that perhaps he should try again in a few hours’ time. He then put the laptop down, and I took him for one of our many walks in the garden. He became more withdrawn during the course of the day. It was as if he was giving up on the fight. It was the last time he touched his laptop.

The Heidi Pieter Alec Badge

2:19PM, Monday, 10 Mar, 2008

Hi there all

I have had emails and even a phone call – we want that badge!!! And though the badge was meant to be a personal thing between Heidi, myself and Alec, after talking to Heidi, I realise there are those of you who want to indicate your support of what Heidi has done for us and therefore, we have decided to give you the link for the badge.

Should you wish to put the badge on your blog, follow these easy steps.

1. Click on the green plus under badges.
2. A window will open. In there you copy and paste the following link: <img src="*http://i239.photobucket.com/albums/ff84/onelp/badge_asp2.gif*">
3. You then click on the "Create badge" button

And Voila, there you have it.

Have fun

Love
Pieter, Alec and Heidi

Notes: I received quite a few requests from fellow bloggers wanting to place the badge on their blogs as well. I spoke to Heidi about it and we agreed that, even though the badge was designed for the three of us, if other bloggers wanted it on their blogs, they could put it there.

To me it was also important that Alec could visually see who all have had the badge on their blogs. In my mind, it would encourage him to fight harder, or make his fight easier.

One comment in particular that stood out on this post was a wordplay posted by one blogger – H.A.P = Heidi, Alec, Pieter = Hope, Attitude, Positive.

Another letter to Alec

7:34PM, Monday, 10 Mar, 2008

Dear Alec

Today has not been a good day. It started off well, with you immediately reaching out for your laptop. I got so excited with you wanting your laptop. But shortly after, you retreated into your silent world. Non-responsive, non-comprehensive. Only nodding yes or no when I asked your questions. Silencing me with a kiss when I say I love you.

When I look in your eyes, they look empty Alec. It scares me. Or at other times, there are questions in your eyes. Sad questions. Questions I can't answer, Alec, because I don't know.

I also have my own questions, darling. Will you get better? I believe you will, but with a day like today, it is only natural that I am a bit despondent. In fact there are three words milling in my mind: Faith (belief), hope and trust. Though hope and trust are both very positive words, I regard them as negative. If you say you hope you will get better, to me it sounds negative. As if you doubt you will get better. If you say you trust you'll get better, to me it sounds a bit more positive, but not as positive as I Believe. I believe (faith) to me means absolute faith. Trust and hope leaves room for doubt.

But I am now believing, hoping *and* trusting.

And then there are three more words. They are almost similar – Love, hope and faith. As in 1 Corinthians 13. You have to have Love, Hope and Faith, but the biggest of these is Love. Darling, my love for you will never never never die – never. And that gives me enough hope and faith that you will come right – even if I am scared.

Love you my special man. Get better soon. I miss *you*!
Pieter

Notes: I was very down in the dumps seeing Alec on this day. Alec would look at me with sadness in his eyes, I could see all the questions. Questions such as: “Am I dying?” “Will I get better?”

"When will I get better?" And they were all questions I could not answer. I had to be strong for the both of us, but I also had my own set of fears. The same questions Alec's eyes asked were my fears. I felt so powerless, hopeless, and defenceless at times. At the time I was carrying a lot. I was carrying issues that Martie had. I was carrying issues my sister had. And then there was Alec. I missed him, who he was. I missed us. And I needed to give myself this pep-talk.

"Load Shedding"

8:31AM, Tuesday, 11 Mar, 2008

Hi there all

Shortly after I wrote last night's post, Alec became responsive again. Hallelujah. BUT, it made me think though. And perhaps I needed his unresponsiveness yesterday to reflect on the load I am carrying at the moment. And a load I can only talk about here, because there is no-one else in real life I can talk to. So this morning, as a bit of therapy for myself, I am going to load shed.

Grandma, GF, Aunty M, call her what you want

She is getting more and more and more on my nerves. She HAS to be centre of attention. Some three weeks ago she started with this story. "Why does your Dad not want to marry me?". "Will you ask your Dad to marry me? I mean, I am like a mother to you am I not?". All this while Alec and I are battling to find out what the hell is going on with him. So I explain to her that it is leap year and that she should ask my Dad to marry her on the 29th of February. So she is with me every day leading up to the 29th. Should she or should she not? Only to tell me on the 1st of March that she was only joking.

She always knows better. She gave Simmi a lecture the other day. A visitor to my house. Why? Because she can't do sewing. How many girls are out there that *can* do sewing? According to her *all* girls should be taught the art of sewing from a young age.

She complains that nobody loves her, nobody phones, but when somebody does phone, she gives them the fifth degree!!!! Ungrateful.

And oh yes, the help in the kitchen. It only lasted 3 days.

And oh yes. Dad knows nothing.

Sussa

Ever since Alec has been admitted to hospital, Sussa started this "I feel sorry for myself" thingy. She says all the right stuff – that she knows that she has to be there for me, that she wishes she could do more, that Alec and I are in her thoughts, and then she starts. "I don't want to live anymore. I am dead inside. I can't take anything anymore". Last night she spent over an hour on the phone with me wallowing in her own shit and feeling sorry for herself. All this whilst I have to deal with Alec and this woman above. And I feel like screaming to her – *wake the F up!!* Here is a man, he might be busy dying, *what* he would give to have a life. But I can't. its my sister.

Load shedding complete ...

Alec is much more responsive today than yesterday. We had the shaving session again this morning, which to me was so special.

Sorry for load shedding on you guys. Love your loved ones, please. Yes, I admit, I am tired. Yes, I admit, I do wish this whole thing can be over, that Alec can be better. But it is my cross I have to carry, and I comfort myself in the thought that God will not give me more to carry than what I can handle.

Take care
Pieter

PS: Please please please spare a thought for Lyndatjie and her friend and their family

Notes: I remember being so upset with my sister. I had the task of looking after Dad and Martie, and now Alec. My business was running into the ground. And I had no-one to turn to. She KNEW this. Yet, she had to come and tell me about all her sorrows and how she wanted to commit suicide. It upset me, I could not understand it. On the one hand I had Alec, who WANTED to live, who WANTED to be there for me, and on the other hand she came to tell me HOW she wanted to end it all.

Tell you what, today I feel exactly the same way she did..

I was also distraught about Lyndatjie's niece who passed away.

For Lyndatjie and in Gracie's memory

9:36AM, Tuesday, 11 Mar, 2008

Hi there
I am taking the liberty of cutting and pasting Lyndatjie's latest post as is. I have read it to my family, including Alec, and all of us had a good crying session. I think it was good for Alec to cry. He could get rid of a lot of his frustrations. And it allowed me to cry as well.
Lyndatjie – you, and Gracie's family, are in our prayers and thoughts. We love you. And as promised to you telephonically – Alec and I will work hard to honour Gracie's memory!
Love
Pieter.

Lyndatjie's blog

Thank you to everybody for your extremely heartfelt posts and messages about my beloved god-daughter that was lost to us on Monday. The method that was used to take her from us was incredibly cruel and difficult to deal with, but the memories we have of Gracie will be our comfort in this dark time.
Every time the searing pain of her loss threatens to overwhelm me, I try and think of one happy Gracie memory to try and bring me back

from the brink. I can't speak without crying and I can't think of her without feeling the physical pain of her loss. Her mom, my best friend, is still under heavy sedation and her father has visibly aged overnight.

In our religion we do not wish for retribution nor do we demand justice for a life taken. Hatred and regret will eat at our souls and destroy the Miracle of Gracie in our hearts and minds. I pity the criminals that took her life so callously. They started off with car-jacking as their true motive for the attack, but unbeknownst to them, they destroyed the most precious gem in the process. I know her spirit would not have been broken by the rape and the brutal attack that followed, because our Gracie had such a bright and beautiful inner light shining from her for all the world to see.

In memory of Gracie

This beautiful girl was studying to be an Occupational Therapist so that she could specialise in helping trauma patients with brain injuries. She chose this field to help her twin brother who suffered brain damage four years ago in a cycling accident.

Right now she was helping me gather information to give to Pieter from *JessyJungle* to assist with Alec's recovery. When we spoke on Sunday Morning she was incredibly excited because of the many articles and activities that she managed to put together for them. She followed their heart rendering story with great sorrow, but also with a quiet determination that where there is life there is hope.

I can't bring my Gracie back, her body was just too broken to be healed. However, I need you all to help me do one thing in Gracie's memory. She had such a beautiful spirit that her only thought was to help people and the fact that her notebook with all this information to help them was stolen along with her car, would have been devastating for her. Could I please ask those that can to find one article about helping patients with brain trauma or activities geared towards assisting them with their recovery? Little games that can be played, or toys that can assist them growing new synapses or even word games that can help Alec to exercise his brain and become strong again.

While we mourn Gracie and the senseless act that took her from us, there needs to be something good happening somewhere out there, to show us that the spirit of our Gracie is still doing good work for those in need. Help me please to celebrate her life and her achievements by turning something bad into something exceptional for somebody else.
We need to celebrate life – so please lets start with Alec.

Notes: I was very shocked to have read this blog post by Lyndatjie. I felt so much grief for her.

Some time before, Lyndatjie had told me that she was putting something together for Alec, to assist him in acquiring his skills again. But she did not say what. Or how. And with this blogpost ALL fell in place. After reading this I disconnected my laptop from the network, went inside the house, called everyone together and read this to them. All of us mourned Gracie's death that day.

Midday feedback

11:42AM, Tuesday, 11 Mar, 2008

Hi there

Glad to announce that things are doing much better than yesterday. I think Alec was just a bit overwhelmed by the laptop yesterday which made him a bit despondent – if I have to guess.

He was very sad about Gracie's death and the lovely post Lyndatjie did, which in itself is not bad. it allowed him to get rid of some of his own frustrations and it help me too, getting rid of mine.

Lyndatjie – my friend, Anne, asked me to please pass on her condolences and to say that you, Gracie and her loved ones are carried in her prayers.

Now this morning Alec completed a balsawood Toucan, a baboon *and* a dolphin. Heidi, tomorrow he will do the butterfly. He is busy practising his writing. And this afternoon our minister (predikant) is paying us a visit.

Thanks – I feel much better after load shedding this morning. And of course the Lyndatjie-induced cry!

You guys and gals take care.

Love
Pieter

Notes: In hindsight, Alec was not despondent about the laptop incident – he was slipping away. There were moments where Alec was lucid, and there were moments when he slipped away into his own world, a world I had no access to. He was overjoyed at times and at other times incredibly sad. And I grew more and more concerned about his deterioration.

Alec was very excited about completing his balsa wood figures. I will never forget his smile when he completed one. He also practised his writing a bit in one of those books one gets for 3-6 year olds. You have to connect the dots. In some cases it went well, in others not, and then Alec would get all frustrated.

Eating, or rather swallowing, became increasingly more difficult for Alec and I tried to make meals that he didn't have to chew – like cottage pies or soups.

A poem for Alec

6:52PM, Tuesday, 11 Mar, 2008

A little poem I wrote today. It's for Alec

Keep well

Pieter

Winter
Stark the tree
Bare
Against elements
Rain, wind, snow
No sunshine warming its bark
Grey skies
An ashen hue
Naked, cold, desolate
White blanket atop the soil
My soul stripped
Naked
Bare
The tree
No leaves of green to adorn
No flower bright
Heart grey
An ashen hue
Lead grey
And in my head a refrain
Ne Me Quitte Pas
Ne Me Quitte Pas
Ne Me Quitte Pas
Ne Me Quitte Pas
© Jessy'sjungle

Notes: Watching Alec struggle to eat this night took its toll on me and filled me with many fears: fears of him going away, hence the "*Ne me quitte pas, ne me quitte pas*" (don't go away, don't go away). I had to take time off away from Alec and be on my own so that I could cry, so I went to my office and typed this poem. Alec did not even know that I wrote it for him; he never got to read it.

When I administered his medication, it was a battle to get him to take it in. He did not want to take the tablets, and I literally had to force him to take it, which made me feel bad. I also had feelings of guilt because I could eat properly and Alec could not.

I battled to sleep that night, so I ended up watching the film *Philadelphia* – and cried silently next to Alec, who slept peacefully beside me.

Let us try and be positive

8:19AM, Wednesday, 12 Mar, 2008

Morning All

Let's try and look at the positive side of things. Alec and I love each other more than ever before. He has lost the 15kg's he wanted to shed, I lost the 10kg's I wanted to shed. Last night and this morning I could feel the first babies in Jessy's tummy. I am tired, but I'm alive. Alec is ill, but he is hanging in there.

Last night was a horrible night for me. I just could not fall asleep. I ended up watching Philadelphia at 11:00. At about 3 this morning my eyes and brain must have decided that enough is enough, you need sleep, and I dozed off. All the time I was awake, Alec lay in my arms, and I just stroked his hair. Whilst he breathed evenly, restfully. I savoured each breath, clinging on to every inhalation and every exhalation.

I have taken to, despite Dad conducting his evening prayers, reading something from the Bible for both of us. And the passage I read *every* night is 1 Corinthians 13. An excerpt for your ease:

4 Love is patient, love is kind. It does not envy, it does not boast, it is not proud. 5 It is not rude, it is not self-seeking, it is not easily angered, it keeps no record of wrongs. 6 Love does not delight in evil but rejoices with *the truth. 7It always protects, always trusts, always hopes, always perseveres.*

and later:

13 And now these three remain: faith, hope and love. But the greatest of these is love.

Alec enjoys it when I read this. And then we pray, in his way he prays along. That is all we can do at the moment.

Did you know that you can now access the Bible on the internet? Such a powerful and useful tool. Here's the link: *www.biblegateway.com.*

Have a fabulous Wednesday.

And *love* your loved ones.

Love
Pieter

Notes: When I wrote this post I was extremely negative. And to get out of the negative mood I was in, I tried to look at the positive. Some time ago, on the 28th of February, a fellow blogger got in contact with Heidi; the fellow blogger's pen name was Ride The Slide, abbreviated as RTS. I will keep their real names secret at their request. RTS offered to take Alec for a second opinion at his expense. Because of the news we received on the 29th, I decided not to take up the offer and rather see what the treatment would do for Alec. RTS however made me promise that should there not be an improvement, I contact him immediately so that we could make arrangements to see a second doctor. This day I decided to take up that offer and emailed RTS. But up until now, nobody in the blogging community except Heidi knew of Alec's HIV status. And somehow I felt it important that RTS must know. Here is the email:

From: Pieter
Sent: 12 March 2008 12:52
To: 'RTS'
Cc: 'Heidi'
Subject: Regarding your offer
Importance: High

Dear RTS

Again from the bottom of my heart, I wish to thank you for your offer. This email serves, in fact, as an investigation of that offer. And since Heidi is assisting me, I do copy her in as well.

Alec's condition started to deteriorate and I feel compelled to take up the offer, but I also have to play open cards with you on his condition. For obvious reasons, I do not blog the whole truth as you will establish. Therefore I am now giving you a breakdown of events.

About 6 weeks ago Alec started to stutter inexplicably. On Monday 18 February he had what his place of work called a stroke. They sent him to the doctor and he performed some blood tests. I took him to my house doctor the same evening who suggested he have a C/T scan and ruled out a stroke. I therefore had to take him to a state hospital the following day. On Wednesday I received a call from the doctor that Alec consulted on Monday with a request to come and see him immediately. He broke the news to us that Alec tested HIV+.

We went back to the state hospital with this news immediately and they confirmed with their own blood tests they had done on Tuesday this to be the case. They immediately tested his CD4 count, results which we would only get on Monday, 25 February.

On Monday, 25 February the results from the C/T Scan showed some form of lesion on his brain. They performed a lumbar puncture and admitted him to hospital. On Wednesday they sent him to Coronation Hospital for and MRI scan and that night Alec's report was lying open for inspection and I saw that they said the lesions are consistent with PML – progressive multifocal leukoencephalitis. A debilitating viral infection caused by a virus resident in our bodies (80-90% of all people) but which only becomes harmful once the immunity system is impaired. Prognosis – 4-6 months to live without treatment, no cure, and only with HAART (Highly Active Anti-Retroviral Treatment) can they perhaps prolong your life to about 2 years, if you're lucky, because 50% of patients with this viral disease react negatively to treatment and it actually infuriates the virus. Doctor spoke to us on Thursday 28 Feb about it and gave us till Friday, 29 Feb 06:00 to make a decision whether we want to opt for the treatment or not.

Friday, 29 Feb, he told us that Alec's CD4 count was way too high for it to be PML. There is a second, viral disease, that mimics PML, called Demyelinating Encephalitis (ADEM for short) and which can both be cured and reversed. The Doctor put him on BOTH HAART and the antiviral treatment for ADEM. Alec did not react negatively to the treatment. Also, I HAVE to state clearly here – Alec does NOT have AIDS BUT he is in the advanced stage of HIV – pre-AIDS, which means with ARV's he CAN lead a good life still and die at 80 of other causes than AIDS.

Thus Alec's medical history (Oh yes I know you are going to ask – am I HIV+ or -, I performed the test 2 weeks ago and tested negative – have to repeat it in 3 months time.)

Now my questions:

In the light of the above – does your offer still stand? What are the terms and conditions associated with this offer? Do we enter into a payback agreement? How do we go about it? I'll be brutally honest – my business has taken a serious knock since Alec's condition started and I am in no way able to afford to pay back immediately. However, my surname in German does mean pride and I am also in no way looking for freebie's or such.

I look forward to hearing from you soon.

Kind regards

Pieter Stols

My cell number is 079-xxx-xxxx

Happy Birthday Heidi!!

11:56AM, Wednesday, 12 Mar, 2008

Hi there all

I am so much wallowing in my own sh!t that I completely forgot that it is Heidi's birthday today.

So I will keep this one short and simple:

Heidi, thanks for all you mean and do for me and Alec and we wish you the most awesome and stunning day.

And in a lighter spirit – something to cheer up *your* day. Eye candy

Love
Pieter and Alec

Notes: Due to copyright issues the picture I had posted may not be reproduced, but Heidi enjoyed pictures of men in swimwear as much as Alec and I did. So we posted her a picture of a rather strapping young man.

RTS phoned me sometime in the afternoon and said that Alec’s HIV status was none of his concern. What was of his concern was that there was a very deep love between Alec and I, which to him was beautiful and which he wanted to try and preserve. He asked that we meet face to face the following day – he was going to put off meetings he had for that day, and that he would drive through from the Rand to come and meet us. He asked for directions, which I emailed through to him.

Wednesday afternoon

3:25PM, Wednesday, 12 Mar, 2008

Hi there

Jessy is in seventh heaven at the moment. She does not know what has happened to her that she deserves a bit of quality time on a weekday afternoon. See, because I was very tired, I needed some shut eye, so I decided to go for a midday snooze. Now if you know me well enough you will realise that a nap in the afternoon is VERY unlike Pieter. I have to be really sick before I can sleep during the day. Reason being that I sometimes suffer from insomnia and should I on the rare occasion take an afternoon nap, chances are very good that I will not be able to sleep that night.

Emotionally the past three days have been very draining on me because unfortunately, though Alec has done some of the balsa wood puzzles, he has been very withdrawn and unresponsive. So much so that I fear for a relapse.

However, Ridetheslide made me promise some time ago that, should there not be an improvement in Alec's condition, I contact him immediately. I do not want to go into any more details now other than to say that Angels comes in very different forms and he is one of them. We are meeting face to face tomorrow to discuss the best way to help Alec and to ensure that he is indeed on the best right medication for his condition.

RTS – Alec and I look forward to meeting you tomorrow. Thanks for coming through to us. When I broke the news to Alec, he started to cry, and of course, I could not help crying either.

But now back to Jessy – she was so chuffed because when I lay down on the bed, I allowed her on the bed and she could assume her *best* position – lying on her back with her 8 nipples pointing in 10 different directions. And both Alec and I felt the babies move – *boy*, you can be rest assured that Milo is the Dad without having even seen them yet, because they are *hyperactive!* (Wonder if you get Ritalin for dogs). If you watch very closely, you can actually *see* them move about.

I just received an email from Anne to me (I'll translate): One seed can start a garden, one candle can light a room. One smile can make someone happy. One person can make a difference. Such a person you are. Now I know that Anne sent it to me to make me feel a bit better, but I am sure that it is much more applicable to people like RTS, Heidi, Lyndatjie, Rose, Blanket, everybody, who helps to carry us through this thing, because at the moment I am of no use to Alec as I am way too emotional and drained. But thank you Anne, I accept it gracefully.

Now you take care – if the insomnia strikes again tonight, I will be on blogland, for sure.

Love your loved ones. And remember – a stranger is a friend you do not know!!

Take care and love
Pieter

Notes: Dad was very amazed that people whom we had never met were prepared to help Alec. In fact, it was beyond his comprehension. He kept on asking me if there was not a catch somewhere. Alec, on the other hand, burst out in tears when I broke the news and because I could not stand to see Alec crying, I cried with him. I was so emotionally drained and tired that day, so I decided to take a rest in the afternoon. It was special, because Jessy was lying on the bed on her back. We could feel the babies move inside her. I could see that this experience filled Alec with awe.

After speaking to RTS I regained my sense of fighting spirit, which I think, rubbed off on Alec as well and both of us actually had a good night's rest.

Thursday Morning

7:19AM, Thursday, 13 Mar, 2008

Morning everybody

Yippee!! It is Thursday. *And* I had a good nights rest. As well as Alec. Strange how certain decisions can affect your life. Sometimes you feel soooooo alone, so lonely, so helpless, so powerless. And you know what you have to do, but just can not do it. Because you're too proud.

But then you reach a point where you realise you are not going to face something lying down, and you replace your pride with faith and you do what you should have done in the first place when it was offered – two weeks ago.

After phoning RTS yesterday afternoon, I took Alec's hands in my hands and told him what I did. And he cried. And I allowed him to cry, he had to get everything out of him. And I allowed myself to cry too. And then I told him to look me in the eye and I said:

"Say after me: We *are* going to make it!"

To which he could only nod his head.

Giving him his medication last night, he was a bit hesitant to take it. And I said to him that he has to take it. I don't want him to die. I told him that he can die the day I turn 80 and he 78. Then we can die together. Until then, he has to do whatever is necessary to stay alive – even if it means he has to take these medicines 6 times a day for the next 10 years. And this brought a smile to his face and earned me a wet sloppy kiss and a huge hug.

I think now that Alec can see I am not giving up on him – he has regained some of his fighting spirit as well. And I am glad about that. And also sorry that I became so emotional. It must have been hell for him to see me so down.

Thank you once again for your messages of support, your thoughts, your prayers, your calls, your comments. Thanks for being you! Blanket and I had a long talk yesterday afternoon, and we are unanimous on this – the support in Blogland is super amazing. There are people on here who feel like life-long friends, *yet* whom we have not yet met. Isn't it just amazing?

I will try (but no promises) to answer some comments individually later today, even if it is in the form of a post. I still have no idea what today has in store for us.

You take care. We love you guys. And remember … yeah yeah, I will say it plenty times more.

Love
Pieter

Notes: My spirits were up that morning. I had a sense that things would get better. The little talk Alec and I had when I administered his drugs, perked him up as well. I could see the admiration and appreciation in his eyes, even if he could not say thank you in words. His communication with me now consisted of yes and no nods, a touch on the arm, a touch on the cheek and a couple of noises. But one could, by the way he looked at you, deduce what he was trying to tell you. You could see in his eyes what emotions he was experiencing – love, fear, happiness.

It was an early morning for us, because we wanted to be ready when RTS arrived. RTS emailed me early in the morning to ask if it was in order if his wife came along too and I said that we'd be delighted. They arrived an hour earlier than the scheduled 10:00. I met them outside and led them into the lounge where Alec, Dad and Martie were waiting. Introductions were made and then RTS told me that his wife is actually a blogger as well; she blogs under the name Ramona. Upon hearing the name Ramona, Alec's face lit up, and it later transpired that she was one of Alec's biggest blog fans.

Thursday PM feedback

1:13PM, Thursday, 13 Mar, 2008

Hi there

I am sure everyone is dying to know what happened. Well. I can not say much, except:

My faith has been restored *big* time in humankind.
I have never in my life met such unpretentious, genuine and sincere people. RTS and his wife arrived an hour early at 09:05 (Thank God) and left shortly before 12:00. And it felt as if we have known each other for ages.
But alas, that is the unimportant bit. The important side is:

We *are* going to get Alec better, by taking him to one of the foremost neurologists in the country. And, this, I am afraid, is all I am going to say about our meeting, by request from RTS *et al*.

RTS *et al. – thank you!!!* Grateful does not even *begin* to describe how Alec and I feel at this point in time. And *welcome* into our lives. God Bless.

Alec is exhausted at the moment and is catching a bit of shut-eye. Our Minister also popped around today as if to bless the day's happenings.

Guys – a bit overwhelmed at the moment and just basking in God's grace. I wish I could give you all a portion of it too.

Love ya all
Pieter

Notes: The meeting went very well. I gave RTS and Ramona some background as to what had happened, what was said, the diagnosis and the prognosis. They suggested that we take Alec to one of the country's top neurologists as a matter of urgency to get a second opinion and to see what course of action could be taken. All this would be at their expense.

Dad then proceeded to show them our garden and Ramona was amazed to see the fresh produce. I picked them some green peppers, brinjals, beetroot, sweetcorn and jalapeño chillies. They were amazed by the baby tortoises and I remember Ramona taking photos with her cell phone to go and show her daughters.

They left shortly after twelve. And just a couple of minutes later our minister from church arrived. We wanted to get Alec confirmed as a member of our congregation. I knew he was a member of the Dutch Reformed Church, but Alec could not remember or tell me which congregation he belonged to. So our minister came over to meet Alec and to help us with the process of getting Alec confirmed as a member of our congregation, and explained what steps he would take once Alec got better. He then said a prayer for us.

Alec ate very little in this period – he struggled with his swallowing reflex. And I was growing more and more concerned about it. I tried to get him to take in some Pronutro with milk, Rehydrat, we even bought ice cream lollies for him to suck on, in the hope that these would help him regain his swallowing reflex.

Later that afternoon Ramona phoned me to say that they managed to secure an appointment with a neurologist at Milpark for Monday the 19th of March. I was very excited, but picked up that the 19th actually fell on the Wednesday and not the Monday. Ramona apologised and said she'd try and confirm which one of the two days it was, but by that time the receptionist had already left for the day and we would only be able to find out the following day.

Alec had a very restless night. I think the day was exhausting for him. He kept on tossing and turning – the whole night. This was something that would become a regular thing in the next couple of days.

Friday morning update

8:17AM, Friday, 14 Mar, 2008

Good Morning all

March 14. Friday. Today was supposed to have been the day before our wedding. I can choose to allow it to make me despondent or I can choose to be positive about it. I choose to be positive about it. We planned a small wedding for tomorrow. Now, when Alec is better, we will still have a small, but slightly bigger wedding than originally planned. And it will happen this year still. And I can't wait ...

Alec did not have a good night, so both of us are a tad tired this Friday morning. But that's okay. We accept and realise you can not have up days all the way. He is seeing the neurologist hopefully on Monday at 12:00, we just have to confirm the date.

Jessy has a new nickname, well in fact two. Sometimes she is called Cow (as in Cow and Chicken), and sometimes I call her Tietietjies du Toit. Both loving nicknames. She is growing like a balloon, and I fear that she will break all records – by delivering a whole rugby team!!

I will try and blog something with more substance a little bit later. In the meantime, please grab a fabulous Friday.

Love
Pieter

Notes: I was a bit sad that day, because it was the day before Alec and I were supposed to get married. It did get to me, but I did not let Alec see.

I was also downhearted, because Ramona phoned to tell me that the appointment was indeed for Wednesday the 19th and not Monday. Two more days of waiting lay ahead. I tried to lift my spirits up a bit by thinking that we got in quicker than usual. Normally neurologists have long waiting lists and it sometimes takes weeks for one to get an appointment.

The third thing that had me down was a phone call from Aunty Fag Hag, who demanded to know why I threw her away. I remember feeling upset about the call and also feeling that she had no idea what I was going through at the time. I felt that if Alec was as good a friend of hers as she claimed, she would have been over to see him since he fell ill on the 18th of February. I nonetheless said I would go over to her place and explain everything when I had a chance during the day.

Substance

9:46AM, Friday, 14 Mar, 2008

Hi there

Something with more substance, as promised.

I actually have a difficult day ahead of me. I mentioned in a blog earlier that Aunty Fag Hag will not be blogged about again. I am however, the type of person that does not carry any grudges *unless* you have *really* done me in *badly*. I'll give an example in the second part of the post. But Aunty Fag Hag first.

We all know that there is no love lost between GF and Aunty Fag Hag. They are sisters in law. However, Aunty Fag Hag has been a confidant of mine since I moved back to Quiet Fountain in 2004. When things became too much for me at home, I had another home where I could just go and let off steam. And I became Aunty Fag Hag's confidant as well. And so she would share her anxieties about her children with me. She would bare her soul to me. She even asked me to marry her – on a number of occasions. And afterwards we could laugh about it. She's just lonely. And I really feel sorry for her.

Some two weeks ago, I just had to get out of the house a bit. Get away from the four walls I call office. And I popped over to Aunty Fag Hag. She told me that her son is getting divorced and asked me not to tell anybody as yet. I told her about Alec and what I discovered in the report that was lying around carelessly and asked her not to tell anybody about it until the doctor has given us the final diagnosis. Both of us reconfirmed to each other that we do not even have to ask to keep what we tell each other confidential. That same night her son in law, GF's son, phones me to pay his respects for the dying Alec. I was furious. Because he said he heard from Aunty Fag Hag.

I have not spoken to her since. That was until last night. She phoned me and wanted to know why I threw her away. I talked around the subject and just got her to calm down a bit. Long story short, I have told her that I will pop over some time today when Alec is having his nap. And then I will tell her that I am disappointed, that she has failed my trust and that it will take me some time to get over it.

Part 2

Something that happened in 2005 can now finally be put to rest. GF surprised me immensely with this bit yesterday. In 2005, a then mutual friend asked me if I could lend him R16 000 to take his adopted son for an operation for his heart condition. I did not have that kind of money, still don't, but seeing that an 8-year old child is involved, I suggested he ask GF who did have ample funds available. GF agreed to lend him the money and a contract was entered into. Said person offered a collateral of his Sound System, should he fail to repay the said amount. Now please note – I did not coerce her into agreeing to lend him the money in any way, but I did act on her behalf though (I handle all her finances – including money she lends to her children, etc.).

We had to claim the Sound System, because he failed to repay the amount of money. We had no use for it so I looked for a buyer. In come two more friends of mine who had their own catering and function business, who said they would gladly take over the sound system. Now they have been friends for yonks and I thought I could trust them. So did Dad; he greatly admired and respected them. They came, had a look, agreed the price was fair, and verbally agreed to pay half of the money 2 days later and the other half at the end of the next month. *Again*, GF accepted this and off they went with the Sound System.

Long story short – we are still waiting for the money. An attorney friend of mine was tasked with writing them up and taking them to task about 6 months later, and eventually we agreed not to throw good money after bad. It would cost us just as much money to get the said money back, so we decided to drop the case (since there was no paper work in place).

Now because they were my friends, I somehow felt responsible because they did GF in, and therefore I told her in 2006 that I would repay the money as soon as possible. I also broke ALL contact with them and do not even want to know how they are or whether they are still alive. I started my own business in 2006 and up till now, have not been in a position to repay the money. Following RTS's visit yesterday, GF took me in her arms and said to me that she is writing that money off. I do not have to repay her, as it was not me that stole the money in the first place. I must be honest, I feel glad that she decided to do it, but the money will remain in my books as outstanding to her, and if at all possible, I will repay it to her. But I do appreciate the gesture.

Anycase – have a fab Friday. Let me work some.

Love

Notes: I was happy about the money being written off. And I was not looking forward to visiting Aunty Fag Hag.

Tietietjies du Toit

11:16AM, Friday, 14 Mar, 2008

Hi there

I have been threatening to post a photo of Jessy for ages, so I took this one quickly with my mobile. Now you can see why I call her Tietietjies du Toit or Cow sometimes. Shame, she must be feeling like a breeding factory at the moment. Sorry about the quality of the photo but you will have appreciation for the fact that this 12kg marvel is lying on my lap behind my desk, at the moment

Off to Aunty Fag Hag now.

Pieter

Notes: I just HAD to write this post. When Alec slept I tried to get a grip on my business, and then Jessy came to lie on my lap. I took this picture of her, so that my fellow bloggers could understand the concept of Tietietjies du Toit.

By now our day consisted of walking in the garden with Alec every so often. Trying to get some substantial food into his body and then some sleeping for him and working for me. Then I would have to cook supper for all of us. Alec always joined me in the kitchen.

My visit to Aunty Fag Hag was not a success. She denied everything and laid it at the feet of Martie. I eventually told her that I was very hurt that she had breached my trust, that it would take me some time before I would be over it, and that the fact that I saw her less often meant that I had my hands full with Alec, who needed my love and my support at that moment.

My new avatar

2:17PM, Friday, 14 Mar, 2008

Hi there,

Seeing that everybody is changing avatars, Jess decided that she does not want to feel left out, and in celebration of her pregnancy Tietietjies du Toit has changed hers to the more ample her.

Okay – Jess is on the bed with Alec here. I have just returned from Aunty Fag Hag and as expected she denied the allegations. Why people deny allegations – in spite of conclusive evidence – is beyond me. But as I said to her – it is water under the bridge. Just know that I was very disappointed.

Alec has just woken up and is watching some National Geographic. Going to kidnap him from the room to take a walk in the garden and to collect some peppers for a cottage pie tonight. Because he has trouble chewing and swallowing, I make food that he does not have to chew, and only have swallow. I also have a problem with one of his pills of which he must take twelve at a time at night. They are vile and bitter and he struggles immensely to get them down. Luckily the pharmacy sells empty capsules, and the pills are small enough to fit six into one capsule. Reducing his pill intake from fifteen at night to five. Hallelujah for technology!

Anycase – have a lovely afternoon and for the non-weekend bloggers – a lovely weekend.

Remember this weekend – *love* your loved ones. Don't just say it, mean it.

Care

Pieter

Notes: Our walks in the garden were always very special for me. Even though Alec was ill, he was concerned about my well being too, and even though he could not help in the kitchen, he stayed with me so that I did not feel alone.

One of my problems was the 12 pills of one kind Alec had to take. Martie actually came up with the idea: Put the pills (it was a small white pill) in an empty gelatine capsule and see if Alec can take them that way. We bought some capsules, and found we could fit 6 of these pills into one capsule. This reduced Alec's pill intake from 15 pills to 5 pills per day. I was very happy about that.

Because RTS and Ramona had now become our benefactors, they asked me to keep them up to speed with Alec's progress; we had some email correspondence that day, in this email:

----- Original Message -----
From: Pieter
To: Ramona
Sent: Friday, March 14, 2008 4:30 PM
Subject: Alec is going for a drip tomorrow

Hi RTS and Ramona

I am concerned about Alec's intake of fluids, so I am taking him for a saline drip at my GP's offices tomorrow. Will ask him to give me some extra for Sunday up till Wednesday, if he can. He is *au fait* with Alec and his condition and pledged his help some weeks ago. I count him as one of my friends – old man but very thorough. Luckily Aunty Martie is an ex-theatre nurse so she will be able to administer the drips, and it is time for me to learn as well.

Sorry – a bit down, don't want to dump on you, but feel the need to keep you up to speed with what is happening.

Take care and a fab weekend for you.

Love

P

PS: Once again – thanks.

From: Ramona
Sent: 14 March 2008 18:40
To: Pieter
Subject: Re: Alec is going for a drip tomorrow

Hi Pieter,

Sorry for the delay, I had my parents over, and I couldn't stop telling them about the fantastic vegetable garden you all have! Luckily, I had 1 brinjals left over, and my dad is going to prepare it for dinner for the two of them tonight ... So from them – Thank You!
Okay, firstly, we did NOT hear back from Dr. F, and by the time we called, they were already closed. I told RTS that we should call again on Monday to bug her for an earlier appointment, but he reminded me that the Receptionist had already gone out of her way to book the appointment we DO have, seeing as the next available appointment was only in April. So, okay lets stick with that. (When you get to know me, you'll find I want everything done NOW!!) LOL

Secondly, excellent thinking on your part to get him a drip. I would never have thought of that. The last thing you need now is for Alec to get dehydrated! Luckily you have Tannie Martie there, which goes to show that everything DOES happen for a reason!

Pieter, please don't feel that you're dumping on us. We spend every waking moment thinking and talking about you and Alec. We have been worried about the situation even BEFORE RTS made contact. We will together get through this.

You know, I never thought I'd meet another couple that love each other the way RTS and I do, but I'm thrilled to tell you that I think we've found them!

I can't wait to see you all next week, but until then I'll be in touch – and please do the same ... anytime day or night for whatever you need.

Please send all our love to everyone.... it can only get better from here.

All our Love,

Ramona and RTS

From: Pieter
Sent: 14 March 2008 19:16
To: Ramona
Subject: RE: Alec is going for a drip tomorrow

Hi Ramona

No problem about Dr F. I really appreciate the efforts you guys are going through!

Ja it was actually Aunty Martie who sorted out the matter of the 12 pills Alec battles to take. They are small enough to fit into empty capsules, so I could reduce the 12 small pills to two capsules. Got rid of the ugly taste AND the quantity.

Grab yourselves a fabulous weekend and I will update you on Alec in the morning again.

Love

Pieter (and Alec of course)

I did make the cottage pie that night. But I did not know that night that it would be the last time Alec would eat cottage pie in his life.

And he had only two mouthfuls.

This is important to me, because Alec never once complained about my cooking. Not that I am a bad cook, no, but because he was so grateful to have someone else cooking for him. And whilst he was still healthy, when I made cottage pie, or macaroni and cheese or bobotie, I always made enough so that I could pack him lunch for the next day – something he enjoyed immensely. Alec was a healthy eater, not fat, no, but he enjoyed his food. You can imagine the impact Alec's not being able to eat, would have on me – the food would become thick in my mouth and I would push my plate away.

I have lost my love of cooking. Forever.

Nighty night

8:20PM, Friday, 14 Mar, 2008

Friday night

A quickie to say nighty night. Alec is in his own world at the moment, but calm and restful.

I hope to have a better night tonight than last night.

The dogs are luxuriating on their pillow next to the bed and will have to go out soon.

See all in the morning. Busy day tomorrow – washing that was supposed to have been done today will have to be done tomorrow. And perhaps I'll make some soup tomorrow – if it is going to be as cool as today. And Alec will have to go for a drip tomorrow – I am slightly concerned about his fluid intake at the moment. Eating is not a concern at the moment, but the amount of fluids he takes in, is.

Take care

Pieter

PS: Alec – one day soon you'll read this. And then we will cry with laughter about this difficult time. Promise.

Notes: I really believed Alec would get better. I really believed with all my heart he would be part of the 1% of people who survive.

Saturday morning

9:08AM, Saturday, 15 Mar, 2008

Morning All

First of all – we both had a good night's rest. Hallelujah. And this morning it is overcast and dripping – so the perfect weather to lie in bed and just enjoy the weather. However – no washing today, Alec needs to go for a drip and I have to prepare food. Soup it will be today.

Back to last night. The pill taking went *much, much* easier now that I could reduce the much dreaded twelve pills to two capsules. We have however discovered two things – 1) Alec's jaws have locked – he cannot open or close them. I have a suspicion that it is just a mental thing, though, because he grinds on his teeth during the night and I think it is just a matter of his jaws being sore from being clenched too long. Will speak to Dr H about it this morning. 2) Alec complains about an itchiness in his head. *In* his head, not on his head. It comes and goes. To me it is a good sign. Old folklore has it that healing parts itch during the last phases of recovery and a possible scientific explanation for it would be that the itchiness is an indication of life returning to previously infected parts. I hope I am right. *Errata* – I *believe* I am right – hope sounds too negative. Again I will speak to Dr H about this.

Then we also received confirmation about Alec's appointment from RTS last night. Alec is seeing Dr F on Wednesday at 12:00. Hooray!! Now I am going to do something that will leave RTS *et al* feeling uncomfortable (that is the type of people they are – they do not take compliments easily), but I am doing this so that you can understand how I feel about them (and I am sure Alec as well). Such generous people they are, that RTS cancelled a meeting on Thursday to come and see Alec. So concerned they are about Alec, that we are in constant contact since they left on Thursday. They are forever coming up with suggestions, ideas, words of comfort and encouragement. People like these are very rare (in fact, up until Thursday I really did not think they exist). Yes, we do have an agreement in place that I will protect their real identities. And I will go to my grave without revealing who they really are, but this does not exclude me from telling them on my blog just *how* grateful I am for what they are doing. You guys rock, RTS, you guys rock. In 48 hours you have done so much for, not only Alec, but me and my family, and I will never be able to have enough words that can describe my gratitude. And I have never seen the Biblical instruction – don't let your left hand know what your right hand is doing (not verbatim) – so much in motion as with RTS *et al*.

On that note – time to help Alec with his shower, shave him, brush his teeth, make the bed, go to the doctor, come home and make the soup, and hopefully then have some quality time with Alec.

Oh yes – I will ask Dr H is he can at least supply me with drips for tomorrow, Monday and Tuesday. I did mention that GF is a retired theatre Nurse who still injects herself with Vit B12 and B6 on a regular basis, so she can help with administering the drip – she's in her element in any case if she can nurse someone. And in the past few days I have actually grown to love her, trust her and rely on her, without expectations. Yes, we still have disagreements (things she clings to that happened 30 years ago) but it is my job to sway her from the negative and make her see the positive.

Now you all take care and *love* your loved ones (on this note – Kerneelsie, regarding your comment the other day. Yes, it is nice to hear it back if you say to your loved ones that you love them. But it does not always happen. And yes, they might think it strange when all of a sudden you say to them – hey, I love you. They might even think you have lost the plot. But you know what – that is what love is. Unconditional. It does not expect back the words "I Love you". And in time, your non-responsive loved ones will catch on what you were on about, and love you back too.)

Love

Pieter

PS: Sorry about spelling mistakes in my posts – I'll admit – I am too lazy to spell check ...

Notes: During the night I woke up several times because of Alec grinding on his teeth. And then I would wake him and tell him not to grind on his teeth. He would fall asleep again, and start grinding. Also, the previous evening he was scratching his head a lot, and when I asked what was wrong, he just scratched his head again and then pointed with his finger that the itching was inside his head. In hindsight, it must have been the PML spreading.
I really felt that Alec ought to be on a drip of some sorts. I was concerned about his fluid intake, as it was less than 250ml a day for the 3rd or 4th day in a row. Luckily I had a very good relationship with Dr. H and could discuss anything openly with him. He heard me out and then told me that perhaps I was a tad over concerned. He could however, not answer the two other questions I had (about the itchiness in Alec's head, and the grinding of his teeth). He undertook to speak to his son, who is a neurologist in Israel, about them and phone me back. He never did.

Saturday afternoon feedback

2:31PM, Saturday, 15 Mar, 2008

Ok, so we went to the doctor. And he thinks my fears of Alec dehydrating might be a tad premature and did not feel it necessary to administer a drip. He says that the less than 250ml of fluid Alec took yesterday is more than sufficient at this stage, plus I must remember that there is fluid in the food he takes in as well. *However*, what he did suggest is that perhaps I can freeze some fruit juice until it reaches the Slush Puppy stage and let Alec take that in. He did however give me a script for drips that I can collect from the hospital *should* the need arise. So at least I do have a back door open.

My doctor's son is a Neurologist in Israel. And he undertook to speak to his son this afternoon about the two other questions I had – the itching *inside* the head and the clenched jaws. He will phone me back with what his son said some time later this afternoon.

And whilst waiting in the reception area, I read an article about a woman who had something similar, if not the same. She says her friends and family actually came to pay their last respects, that's how bad it was, *but* she has recovered fully and returned to her teaching job. And I could share this with Alec and thereby recharge his fighting spirit.

In the meantime, I did have to do at least one load of washing despite the rain. And the soup is on the stove simmering away. And I can now finally sit for 10 minutes with Alec. And the rain is pattering down – yummy.

So grab yourselves a *wonderful* Saturday afternoon and *love* your loved ones. Okay?

Love
Pieter

Notes: The article I read was very uplifting. Unfortunately I don't know where it is, or what publication it came from. It was about a woman suffering from Aids Dementia. Aids Dementia is one of the diseases that mimic PML. Her family had left her for dead in hospital, yet she recovered and is living a full life now. It gave me so much hope.

I remember Alec sitting in the waiting room that day. Spit was dribbling from the corners of his mouth and down his chin. I had to wipe it off, every so often. People stared at us and I did not give a fuck. Eventually I had to borrow tissues from the receptionist to wipe the dribble away. She was very understanding and gave me a whole handful. But I remember thinking at the time (and wishing I could scream out loud): "What are you staring at? Would you not do the same for your husband/wife/life partner? It's not his fault."

I remember getting home from the doctor's and forgetting to switch off the lights of my Nissan Bakkie. My Dad later had to do the grocery run at our local supermarket. I was busy doing a load of washing and had a pot of soup boiling on the stove. He came back inside and told me that the bakkie's battery was flat. I had to go out in the rain and push the bakkie so that Dad could get it to start. Not sure what the technique is called. But we battled. At that stage I remember screaming to God, asking Him why He burdened me so much.

I felt desperate – Alec was sick, the bakkie's battery had died, it was raining and I had a load of washing plus I had to do the cooking, and Dad was upset with me because he was hoping I would rather go to Spar instead of him. My sister wanted to commit suicide, and Martie kept on moaning because my Dad was not married to her. It all just felt too much for me and I remember screaming, as I pushed the bakkie "Here, hoekom moet ek so sukkel?" (Lord, why must I suffer this much?).

Little did I know that afternoon how much more I would suffer.

Being scared

9:05PM, Saturday, 15 Mar, 2008

I am not feeling sorry for myself, And I'm not looking for sympathy either. But I am scared. I am really really really scared. To see Alec deteriorate daily. To see him withdraw more and more. To see him eat less and less. And though I do try and be strong, tonight is not a good night for trying to be strong.

Tonight we had a major battle getting him to eat something. As if that was not enough, I had an even bigger battle feeding him his pills. And as if that was not enough, I just could not stop crying when I read from the Bible for us.

Yes, I am drained. I am exhausted. I am ... up! At the moment I am helping Alec to shower. I brush his teeth for him, I shave him. I help him sip his one sip of coffee. and his 2 sips of water. I help him eat (feed him). And I do not mind doing it for him – he is my life partner – through better *and* worse. If only his condition could remain stable and not deteriorate.

Ok, perhaps I am ungrateful. He did eventually drink the pills, plus half of the mango and orange Slush puppy, plus a full glass of grenadilla juice. Which is more than he had yesterday. But the getting him to eat something and then sleeping the whole day (except the bits we spent at the doctors). It is heartbreaking for me. Six weeks ago, this man still walked normally, now he has to cling to me for support. Six weeks ago he could not stop talking about the upcoming wedding. Now he cannot speak one small sentence. Can only nod yes and no.

The guy that six weeks ago decided to go on a diet because he weighed 100kg, now weighs 85kg.

And as he clings to my arms whilst he is sleeping, I am riddled, no plagued, by thoughts of "what would I do if he dies tonight" or "Why him? He has not done anyone harm!" Or with thoughts of – at least he would know he was loved if he goes. At least I could make sure his last days were as pleasant as possible.

I really do not know what to pray anymore. Except that God's will be done. but I am scared of what God's will might be.

Ag, perhaps I should stop writing this post. Do not want to make you negative at all. Just wanted to share some of my anxieties.

Lets hope that Alec feels better tomorrow. Lets hope that it is the last bad spell before he starts showing improvement. Often before improvement sets in there is a severe deterioration. Lets hope this is what we are experiencing now.

Love your loved ones, *please*. I beg you.

Love
Pieter

Notes: I was feeling out of it when I wrote this post. I had tried to feed Alec some soup, but he would not eat. If he had a few mouthfuls it would have been a lot. I would try to encourage him to eat a bit more, but in hindsight I think he must have seen it as me fighting with him.

I was feeling very sorry for myself. At this point, I have to admit, I wanted this thing to get to one point or the other. How can one explain that feeling? The feeling where you give everything you've got, your time, your money, your body and your soul. Just so that someone could get better.

I would have these conversations with Alec, explaining WHY he had to eat. Why he had to go on. And then I would ask him if he understood. And he would nod yes. But when I brought the spoon closer to his mouth he would nod no. And then, after I had fed Alec, I had to go and have MY dinner. How could I eat? If my loved one could not eat, how could I?

I was desperate. I wanted Alec to see that I loved him (not that I doubted he did not). But I got absolutely no reaction from him. Nothing. That is why I typed in capital letters LOVE your loved ones. PLEASE. I beg you. But I could not blame Alec. It was not his fault.

Sunday Sunday

9:29AM, Sunday, 16 Mar, 2008

Morning all

Hmmmm. How's this weather? Perfect let us stay in bed weather. And that is precisely what I plan to do.

I am still feeling drained. Empty. But there is a glimmer of hope and I desperately cling onto that. Alec had breakfast and his morning pills without putting up a fight. And as a reward he can have me the whole day in bed – next to him, and he can sleep to his heart's content. Sleep is good so hopefully it helps.

On the menu for today is comfort food – chicken a la king. Nice and soft and not chewy, so easy to take in, and I will just get up every so often to go and check on it once I start preparing. As for the rest, we can just watch TV, I can surf the net, and just do sweet twiddle dum.

Take care and we'll catch up a bit later.

RTS *et al* – thanks for the email this morning – it meant a lot to me. Lornagh, thanks for yours as well, it was just what I needed last night.

Love
Pieter

Notes: It was yet another rainy day. A day that prohibited us from taking our usual walk in the garden. My fear was that if we did, Alec might catch a cold or get the flu. So I kept him indoors. And that only aggravated everything. RTS and Ramona and I had some email correspondence on this day. They wrote:

From: Ramona
Sent: 16 March 2008 08:44
To: Pieter
Subject: Good Morning

Good Morning Pieter.

I hope you had a good rest. I read your blog, and understand that you are a bit down, I hope you're feeling better today.

Anyway, I just wanted to let you know that I'm thinking of you and your family ... Every day is a step closer to Alec's recovery.

Have a blessed Sunday with your loved ones.

Loads of love and hugs to everyone.

Ramona

To which I replied as follows:

From: Pieter
Sent: 16 March 2008 08:56
To: Ramona
Subject: RE: Good Morning

Hello my friend

Last night was really bad, I'll be honest. Alec refused point blank to take his meds. And he was clinging to me like nettle to fur. This created the feeling (and I am sorry about it) that he was on his way out. I cried a lot and it was only when Alec saw my tears, that he started co-operating again. Glad to say he did in the end take his 5 capsules, drank a glass of water, a glass of juice AND had ½ a glass of slush puppy. I think the slush puppy is the way to go.

He is sleeping a lot, but sleep is good.

I am hanging in there – on the brink of a depression but refuse to succumb to it. Neither Alec nor myself need it right now.

Going to make some chicken a la king today – simple, soft and wholesome.

You, RTS and the kids grab a stunning Sunday as well

Love
P

I was still making food that would suit Alec's condition. But he refused to eat it. Well, not refuse, he just couldn't. He could not eat anymore …

The psychology of healing, grieving and dealing with bad news

11:00AM, Sunday, 16 Mar, 2008

Hi there

I've been wondering about the grieving process, or the process during which one comes to terms with things such as bad news or illness. It is said that it is typified by five stages: **D**enial (this isn't happening to me!), **A**nger (why is this happening to me?), **B**argaining (I promise I'll be a better person if ...), **D**epression (I don't care anymore), **A**cceptance (I'm ready for whatever comes).

I am not sure where Alec and myself are on this scale with this thing that is happening to us. I suspect, and I might be wrong, that Alec is a little ahead on the scale more than I am. I think Alec is at the Acceptance stage, whilst I am at the Despair or Depression stage.

The reason for me saying so is that last night he refused point blank to take his medicines. And this has made me intensely sad. So much so that I just burst into tears out of sheer frustration, anger and despair.

In a sense I think it was good for him to see me like that, because it woke something up in him. He immediately decided to take his pills, one by one, he drank a glass of water, a glass of juice and half a glass of slush puppy.

This was continued this morning, he had a cuppa soup for breakfast, took his pills one by one, *and*, when we got back into bed, he took one of his Easter eggs and ate that. Out of his own free will, not me nagging him to do so. Alec is a smoker, as am I, and for the past three days he has not smoked more than three cigarettes. However, he just asked me for one. Though I am anxious for both him and me to stop, ex-smokers testify to the fact of anxieties forming when you try to stop, and I don't want anxieties in his life right now. I need him to get better.

I am also thinking about a novel written by Dolf van Niekerk. Afrikaans readers who attended high school in the 80s will most certainly remember it. *Die Son Struikel* (the sun stumbles). The main character in the prose, Diederik Versveld, has this thing about seeds that first have to rot before the plant can grow out of it. Strange that I should think about this book now, because at school I hated it. It was difficult, and the Afrikaans teacher we had always smelt of booze when we handled this book. But in a strange way, I wonder if it is not true, that Alec first had to deteriorate so that a newer, better Alec can grow out of it.

I'll be honest, I am going through hell, yes, but I face it as a challenge; a test God has brought over my way, to reassure my faith, my loyalty to Alec and my love for Alec. At the moment I allow Alec just to be. He can cling to my arm as much as he wants. He can snuggle up in my armpit, as much as he wants. I will be there for him. And I am going to stop trying to be a demi-God. I am going to allow myself my fears, my frustrations. Because I am human. I am entitled to them. And perhaps, by realising this, I am helping myself too by giving me the power over them. What is that old saying? “God grant me the serenity to accept the things I cannot change; the courage to change the things I can; and the wisdom to know the difference." – *Reinhold Niebuhr, The Serenity Prayer.*

Love
Pieter

Notes: I remember that I was very angry with Alec for not wanting to take his medicine. When I wanted to give it to him, he just shook his head “No”. It was very clear he did not want to take the medicine. And it broke my heart.

We had promised each other on the 28th of February that we were in this thing together, and now he did not want to do it. I did not fight with him; I just reminded him we had promised each other. And then I started to cry. I guess the sight of seeing me crying had the same effect on him as his tears had on me.

I also recall that on this night, I actually contemplated lighting Fumitabs in our room. So that Alec and I could both die together. But I did not want to. We still had to go for that second opinion and rule out PML and confirm another disease ...

It was also the day that perhaps, in a way, I gave up. Where I realised that this thing was NOT in my hands and that I must let what must be, just be.

Some questions answered

2:04PM, Sunday, 16 Mar, 2008

Hi there

Granny just posed a question and Napier asked the same question some time ago. Perhaps now is the time to answer it.

Granny asked, "Do we now know what is wrong with Alec?" and Napier asked a couple of days ago, "Do we know yet what virus caused this?"

Granny – no, we are still with one of two diagnoses – both neurological in nature, hence Alec seeing a neurologist this week, both caused by virus resident in your body.

PML – Progressive (ongoing) Multifocal (various locations) Leuko (white) encephal(o) (Brain) itis (inflammation).

A terrible disease caused by the JC virus which is a resident in the kidneys of approximately 90% of people. Under severe conditions it attacks the brain and leaves lesions which cannot be cured, reversed or treated. No known cure exists, and with current experimental drugs your chances are only 50/50 for improvement. Without the trial treatment, you have 1 - 6 month from diagnosis to live. Only about 2% of people get this. It is not contagious.

DE – Demyelinating Encaphilitis

A viral disease caused by a suppressed measels virus resident in about (yep) 90% of people. (Yep) under severe conditions it attacks the brain and leaves lesions which *can* be cured, reversed and treated. DE mimics PML, but where PML is typified by a low protein count in the blood, DE is typified by a high protein count. I could not find out how frequent this disease affects people, but it is also not contagious.

The reason for us visiting the neurologist is to obtain a second opinion. We believe it is the DE and we believe that with the help of a top neurologist, Alec's chances of a full recovery will be improved vastly. The MTM (Manto Tshabalala Msimang) hospital did not rule out one of the two diagnoses and plan to do so only some time in April. They have not equipped me on how to best care for Alec; they just said "Here he is, he is discharged, bring him back on the 2nd of April and again on the 9th". Though I cannot complain about the care Alec received whilst he was at MTM, there was no follow through and aftercare provided.

So that is that in a nut shell. It is not diseases you pick up from visiting the mall, or from kissing someone who's got it or anything. it is caused by bugs living inside your body that just take the chance when the opportunity arises and conditions are right for them to do so. Scary hey?

I do hope it answers some of your questions.

This would be my last post for today! You take care and we will see you in the morning.

Love
Pieter

Notes: I knew when I named Alec's condition I would open myself up for debate, but too many questions were being asked, so I could not avoid answering it. So I tried to play it down by STILL leaving the HIV issue out of my post. I was very evasive when I wrote this post. I gave just enough information without giving too much. I did not want Alec to be upset with me about revealing his HIV status when he got better, which I still believed he would.

Too good not to post ...

5:25PM, Sunday, 16 Mar, 2008

I know I said I will only post again tomorrow. *But, But, but, but.* If you have been living as close as I have to Alec for the past couple of weeks and especially the past couple of days, you'll know that Alec has difficulty eating. Specifically difficulty chewing his food. Which led to me changing our diet from the steak and chips or "whole" food scenario, to simpler food that does not require chewing, such as mash and mince, soups, etc. All he has to do is swallow.

It is also as if his brain "forgot" the routine to swallow. In other words, he would put food in his mouth, but then not swallow it. Until his mouth is stuffed with so much food that you actually have to remove it with your finger. Sounds gross, I know, but it is part of the reality of Alec's condition, and I am used to it by now.

Now – the good news. I made chicken ala king for lunch/dinner today. And Alec took his first tentative chews. It is the first time in a week that I see him chew!! And I am ecstatic. I am over the moon. You know, when you pray for small little signs to see that we are making progress? This is one of them. A small little sign. You see, why is this important for me? If it is PML, then that part of the brain would be destroyed and can not be recovered. If, however, it is DE, that part of the brain is injured, but can heal.

Thank you God, for giving me another blade of grass to cling to. Thank you.

Okay, and now I will only blog again tomorrow. Have a lovely rest of your Sunday.

Love
Pieter

Notes: I was over the moon that Alec had attempted to chew. I was very concerned about him clenching his jaws, and his continual teeth grinding. But in the end Alec had only 2 or 3 mouthfuls of food.

I realise that at this stage I was actually living past Dad and Martie. They existed in the house, yes, but I did not speak with them often, as I was between the kitchen and Alec most of the time. The only stage we had a meaningful conversation was at the dinner table. But unlike the normal days when Alec was still healthy and everybody would stay seated until everyone had finished eating, I got up as soon as my meal was finished.

A special memory I have of Alec – though we had been very close since we moved in together – Alec developed a new habit:. He would grab my right arm in bed and hug it whilst sleeping. And most nights he would sleep in my arms.

Monday morning – Day 0-2

9:16AM, Monday, 17 Mar, 2008

Morning all

Day 0-2. In other words, 2nd last day before we see the neurologist.

Both Alec and I had a good night. Thank you. He did have trouble swallowing his pills last night, but in the end all went well. And as a reward, he got to sleep in my arms the entire night. Not really a reward, but Alec has taken to sleeping in my arms (more so than in the past) as of late, and it is so precious to me.

Since the weather is as bad as it is, we keep the man confined to bed, and I actually decided to move office into the room for a while, so that I can be close to Alec.

I am still very optimistic about the first sign of chewing I saw yesterday afternoon, and explained the consequences of this small step to Alec. I am sure it encourages him too.

I have not said this recently, but wish to say it now, again. Thank you sooooo much for your words of encouragement, your thoughts, your prayers. I see a lot of badges on other people's websites, and it is so encouraging. I am humbled, but at the same time proud, to be part of this community.

Will do an update again a bit later. Time for Alec's breakfast, and then it is shower time for the two of us. Whilst in the shower the house executive has to put clean linen on the bed so that all Alec has to do is get into a nice, freshly made bed.

Enjoy your Monday, wherever you are and whatever you do. Life's too short not to enjoy it. And l*ove* your loved ones. okay?

Love

Pieter

Notes: This was the day that I decided to move my office from the outside room into our bedroom, so that I could be with him 24/7.

Tending to Alec by now was a full-time job. Not only did I have to shower him, I also had to help him in the loo. Sometimes he would miss the loo if he went on his own, and then I had to clean up afterwards, so in order to save him the embarrassment I made a joke out of it when he needed to go to the loo. I would say something like –"if girls can go to the loo together, why can't we?", and then Alec would get that sheepish grin.

This Monday and the Tuesday I mostly sat with Alec on the bed, or sometimes next to the bed against the window. I remember it being so cold that I had to sit under a blanket. It was also on this day that one of our fellow bloggers phoned me to apologise if he created the impression that he did not care. Apparently another blogger had left a comment on his blog asking him where his support for us was. I reassured him that we appreciated his friendship and his support. Then the blogger who left the comment on the first blogger's post phoned me as well. Her brother was the late Braam Kruger. We had a long and good chat, though the content of that chat escapes me.

TWO thoughts for the day

10:55AM, Monday, 17 Mar, 2008

Hi there all our wonderful blog friends

Some time ago I posted a post about why I am doing what I'm doing for Alec, and in there I assumed that it is a natural thing to do when it concerns your life partner; be it male, female or same sex. A few people said to me that it is only a few and far between that would do it. Which makes me think about the fibre of relationships. Why do we enter into a relationship? Why do we say, for better or for worse, but when for worse happens, we run away?

Okay, I over generalise with the "we", because I am not running away and a huge part of me wants to believe that neither would you. But I do want to leave you with one question. A long-winded question, but it is the principle that counts and perhaps it could be your thought for the day.

If your life partner/husband/wife/father/mother/brother/sister/ Mother/Father-in-law gets a debilitating disease – how far are you prepared to go? Will you be prepared to go to the toilet with him/her and assist? Will you brush their teeth? Will you shower with them to help them to get clean and thereby retain their dignity? Will you feed them with a spoon to ensure that they do not choke? And to ensure that they at least get something in to eat? Are you a friend for the better and for the worse?

An answer of no somewhere? If so, revisit my post I made end December about Aristotle and friendships aka relationships and the principles thereof. And then ask yourself – do I really deserve this friend's friendship if I am not prepared to go *all* the way for him?

One thing Aristotle did not address in his Nichomachean Ethics, or perhaps I missed it, are the RTS's in the world. Complete strangers, prepared to help, no matter what.
Look, I am no saint – I am the first to admit. But I was under the impression that this kind of thing happens naturally, forms part of the moral fibre of our society, or am I wrong?

Another thing – I will not mention names and please do not get me wrong by thinking it is a fight, I beg you. I do not sit with a list of names and tick every time someone leaves a comment of support and the person who leaves the most comments of support get a gold star or a silver star or a bronze star. I do not sit with a list of telephone numbers and note every time someone phones or send a fax (yep, I even get faxes in support of Alec). The mere fact that you are thinking of us, you don't even have to leave a comment, you just have to think of us, means the same amount to me as what HeidiL's visit and RTS's support means to me. I do not take to idolising people and putting them on pedestals. For instance, if Hutton leaves me a ";-)" as a comment, it means exactly the same to me as when someone says "I am praying for you". And if you leave a comment once every two weeks, carries the exact same weight as 10 comments a day.

I raised this specific point because one of my friends phoned me and said that s/he received a comment on his/her blog from someone else, asking where his/her support for me and Alec was. And this friend felt in doubt that s/he is not doing enough. Therefore, categorically, I thank *each* one for your thoughts, comments, support, emails, faxes, telephone calls, visits, help, irrespective of it being once, twice, 10 times a day, week, fortnight or month.

That, my dear blog friend, was me – unplugged. *Thank you*, I will never be able to say it enough. But then, I did say I am not keeping score either. So sorry if it bores you to death?

Love you *all.*

Pieter (and by default Alec) – (oops, not forgetting Tietietjies du Toit)

Notes: We really received such a lot of comments and support on my blog that it was a matter of impossibility to pay attention to each one individually. But I felt it important that people should know that we appreciated each and every comment we received.

Sometimes one can be stupid

1:32PM, Monday, 17 Mar, 2008

Hiya

Please don't think I fought with anyone in my previous post. I did not. Okay? I love you all and everyone who thinks of us has a special place in my heart.

I feel like a twat. *Stupid*. Why? You see, I looked at Alec through my "being healthy" eyes and up until yesterday gave him three big meals a day. Breakfast, lunch and dinner. But following his first tentative chews of yesterday afternoon, something (could it have been God? I'm sure it was) said to me – "You know Pieter – you ought to give Alec six small meals spread through the day". And so I listened to this voice. And decided to start today. And I also decided that instead of him feeding himself, I am going to feed him.

Now this was a difficult one for me to do. Why? Because a few of us had this telephonic discussion about Alec retaining his dignity, etc. etc. etc. *But*, it is one thing allowing someone to retain his dignity but in the process cause himself harm by overstuffing his mouth, and quite another to allow someone to get in enough vitamins, proteins and the stuff that matters in order to get better.

So I sat Alec down in bed this morning and explained to him that I prefer to feed him, and that he must not feel bad about it, that I know he would have done the same for me had I been in his situation, and that it is only until he is better. And you know what, he gave me the most beautiful smile you can imagine. Plus, it made it easier for me to administer his morning pills, because I could just slip them into the teaspoon full of porridge I gave him. I gave him some yoghurt earlier and some reheated soup just now and it is going *much, much* better with the eating. By the time he gets tired (and then forgets to swallow), he already has had a sufficient quantity of food, alleviating the frustration of not being able to swallow.

Today is such a special day for me. Because it is so cold here (winter), I moved office to the bedroom, diverted the office phone to my cell, and voilà, I can spend the day with Alec. And we have the TV on his favorite channel, MTV (see Jakkalsblou, I do listen). I am sitting on the floor with a blanket covering my legs, Jess is lying between my legs under the blanket, and Milo lies at my feet.

I also feel a little bit compelled to react to some comments on my previous post. Rose, Liz and Poppiekreer. I lost my mother to a stroke and helped her through her passing. Same with my grandmother on mom's side when she had her heart problems. I washed her fragile body, rubbed cream into her dry skin. Yes, we do what we have to do. I am helping Alec now with the hope, trust and faith that he will get better. And I will do it for my dad, Aunty M and Sussa if ever she needs it. Thanks you three for sharing your experiences with me and Alec.

Now, back to work.

Love
Pieter

PS: No *psell cheque* done!

Notes: One of the comments I received on this post really touched my heart, because in essence it is exactly who I am:

I know where you come from, Pieter. If Alec's life depended on it, you'd give up your life in a heartbeat. True that is very rare in the materialistic world we live in today, but you're a true human, true to yourself and your loved ones and therefore you deserve the respect and love of your friends and supporters. Glad to know you ... love, SN

I decided on this day that I was going to take over Alec's feeding and feed him myself. It was a rather difficult decision to make, because between Dad, Martie, Annemarie, Heidi and I, we felt it important that Alec must retain his dignity by trying to feed himself. But it was also unbearable watching him suffering to swallow or seeing him spilling his food that he so concentrated on not spilling. So my reasoning was if we gave him six smaller meals, by the time he got frustrated with swallowing he would have had enough food in him to last him till the next meal. Also by feeding Alec myself, it made it easier to administer his medication – something that was gettingworked increasingly difficult. One thing that tremendously well with Alec was semi-frozen fruit juice – I called it slush puppy. He could not get enough of that!

Whilst Alec was sleeping, I rummaged through our photos of our Zambia trip and became very nostalgic and downhearted, and so I posted the following of him:

Don't scratch where it doesn't itch

3:44PM, Monday, 17 Mar, 2008

Hiya
We have a saying in Afrikaans that goes – Moenie krap waar dit nie jeuk nie. Don't scratch where it does not itch. I did that this afternoon. Why, I don't know, but it has left me a little bit sombre.

This pic was taken on the Zimbabwean side of the Victoria Falls, and was one of the most beautiful sunset cruises I have ever experienced. And having had the privilege of having Alec with me, made it so much more special.

Just thought I'd share it with you.

Love
Pieter

Notes: I missed Alec immensely that day and went through our photos. I still do it today, when the longing becomes too much.

But this day I decided to put a face to the name for my fellow bloggers. I also decided to do it so that people could see why I was so frustrated with Alec's condition.

Too good not to blog about it – part 2

6:53PM, Monday, 17 Mar, 2008

Hi there

Not sure whether I must laugh or whether I must cry. So I am doing both, at the same time. Why?

Earlier this afternoon Alec showed *true* emotion. He watched a sad movie, and he cried. And now, with 7de laan on the screen, he burst out laughing at Matrone and Esther and Skip aka Bismarck.

a) It was nice to see him laugh. In fact, more than nice, it is friggin fantastic!!
b) He can really really really understand what is going on around him. It is as if he is coming out of this really bad dream.

Thank you God, for *another* blade of grass.

Love

Pieter

Notes: I can't remember which movie Alec watched, but it had him very emotional. And when Alec cried, I cried too. But the important thing for me was that Alec showed emotion and the right kind of emotion at the right time. This importance was reiterated when Alec started laughing about the antics on 7de Laan. It was a funny situation and Alec exhibited the right kind of emotion by laughing at their antics. This really perked me up tremendously. I remember receiving the following comment on this post from RTS:

Both Mrs RTS and I are more than pleased to hear this.
Upon which I sent them the following email:

From: Pieter
Sent: 17 March 2008 19:54
To: Ramona
Subject: For Mr and Mrs RTS

Hi Mr and Mrs RTS (you had me chuckling with that one)
So you've read. Me is over the moon. The fact that he laughed out of his own accord during a funny moment of his favorite soapie, made me burst out laughing too.
Small little things, perhaps insignificant to others, are starting to awaken. I like to liken it to a butterfly in a cocoon. Seemingly dead for so long, and then suddenly you start to see small changes. I think our butterfly will emerge soon.
Thank you sooooooooooooooooooooo very much for your support.
Care
Pieter

Tuesday – Day 0 – 1. AM

9:36AM, Tuesday, 18 Mar, 2008

Good morning.

Alec and I did the triple S routine and I gave him his breakfast already. So strange, I thought to myself whilst in the shower, we never showered together when Alec was still healthy. We suffered from this dreaded "but what will Dad and Aunty M say" disease. Now, that he is ill, we shower together every day, and nobody says a word!! Chances spoilt hey. Chances spoilt.

Porridge and pills went well this morning, as they did last night. Aunty M, bless her soul, got this bee in her bonnet and decided to grind the twelve pills to a powder and put it in an empty capsule. So, we could reduce the two capsules containing six small pills each to one capsule containing the powder of twelve pills, thus reducing Alec's pill intake from five at night to four!

It is once again cold this morning (Little L you asked where we stay – well we stay in Quiet Fountain close to Klerksdorp and the place that never snores) so office is still in the room with Alec. Armed with cell phone and laptop and all relevant documents I need, it is actually quite fun working in the bedroom.

Funny how this whole thing with Alec has bonded our family together. Aunty M and I are closer than ever before, and every so often she just pops into the room with a cuppa for me and a glass of juice for Alec. In regards to feeding Alec, I see oftentimes now that, as I bring the spoon or fork to his mouth, he will take my hand in his and direct it to his mouth. I regard this as a very good sign. Shows he wants to start taking control again.

My dear bloglander friends – again, and don't get bored with this please, *thank you so much* for your support. I do not know what I would have done without it. And *please* accept my apologies for not answering each comment personally. As much as I want to, I simply just do not have the time. *But*, remember, that I (and by default Alec), appreciate each little comment immensely.

Now you have a terrific Tuesday, and remember, *love* your loved ones.

Love
Pieter

Notes: I have to be honest, when I reread this blog post, I was caught off guard a bit. How could I forget? How could I forget the way Alec grabbed me by the wrist when I tried to feed him – directing either the spoon or the fork to his mouth? Like a malnourished baby? In a sense it was great to experience, it gave me hope. But it also had its down side – I felt as if I was under-nourishing Alec. As if I did not give him enough food. You would ask him if he had enough, and he would nod yes, but swallowing was a problem for him, and perhaps he just nodded yes to get rid of the food? I always tried to give him more than he could take. It was important to me. Because he WAS going to get better.

I was very chuffed with Martie for discovering that if she ground the 12 pills to a powder, we could fit all twelve into one empty capsule. She sat and did this doggedly for me. And every so often, when her hands were aching, she would get up and make Dad and me a cup of coffee, and bring mine to the room, along with a glass of juice for Alec.

Emotions during the sickbed of a loved one

11:15AM, Tuesday, 18 Mar, 2008

Hi there

I was watching an Air Crash Investigation on the National Geographic Channel recently, when one woman made a remark on how she felt being a victim of an air crash which was caused by poor maintenance on the aircraft. She said that for her, the world came to an end, and she had major problems accepting that life was actually going on all around her.

Strange that that is (was) exactly what I felt when Alec fell ill. Yes, I know work must continue, I have a household to run, friends and family to appease. But when Sussa for instance starts with her nonsense of not wanting to live anymore, I felt like *please, give me a break*. Or people started nagging for quotes, I felt like "But can you not see what I am going through?". But how would they know in any case if I don't tell them? And what I found was, that if I tell them what I am going through, they actually *do* understand and become *less* demanding.

So, *hence*, I discovered, communication is the way to go. Talk about your situation. NO, they are not going to take your frustrations and anxieties away, *but*, it will bring understanding and patience. Even *inside* the house, I found that a simple "I don't feel up to it today" brings a whole lot of understanding and therefore help.

Another thing that I found was people coming forward with – My mom / dad / brother / sister / close relative had something similar. And then those people start sharing their experiences. Someone even suggested that I gave her courage to finally face what she went through with her Dad some time ago. And that, to me, is actually very encouraging. It gives me the feeling that I am *not* alone, and that my situation is not unique.

What it does fails to do, however, is take away this feeling of utter helplessness sometimes. Where you feel you just can not take anything anymore. But that too, has now passed. I just take things minute by minute, realising each and every day we wake up next to each other is a blessing to be cherished, and that all else is irrelevant and immaterial.

Just some of my thoughts and feelings on paper. Sorry, internet, but if you print it out it will be on paper. Okay?

Take care

Pieter (Tietietjies du Toit is ensconced on my lap, and *boy*, is she getting heavy)

Notes: Life pretty much stood still for me at this point in time. I was worried sick about Alec. Sometimes there would be positive signs, but there were mostly negative signs. Most times I chose to focus on the positives and ignore the negatives, but sometimes the negatives got to me a bit.

Alec was the priority in my day and work came second to that. I tried to explain to clients that I would get back to them as soon as possible. Then when Alec fell asleep I would work as fast as I could. But even then, I could not apply my mind to the task at hand. It would constantly drift toward Alec.

By special request

2:15PM, Tuesday, 18 Mar, 2008
Hi there
By special request, some photos of Jessy I took some minutes ago (Not the best quality I know).
1. Lying on her cushion next to the bed.

2. Lying on the bed with me and Alec. See where her name Tietietjies du Toit come from?

So how are we feeling about tomorrow?

Alec just nods his head. Me? I am equally anxious and confident. Honestly I do not know what to expect, and think I will cross that bridge once I get there tomorrow. I am however, thankful that I do not have to do it alone, and that the two RTS saints will be there, with me, holding our hands and giving us the emotional support we'll need.

So – that is it. Off to make bobotie now and then feeding time starts.

Take care blogland

Love

Pieter

PS: Interloper. happy?

Notes: Our fellow bloggers became very involved in our lives and even more so with Jessy's pregnancy. Some photo's were requested which I posted in this post. Dad established Jessy's due date as 31 March.

Should I lie?

4:32PM, Tuesday, 18 Mar, 2008

Should I lie and say that I am unfazed about tomorrow?

Or should I be honest and say that I am actually shit scared?

I have been naughty. I am enjoying a glass of sherry. And Alec looked at the glass with longing eyes. And I gave him a sip. His whole face just lit up and a smile erupted from his stricken face, which made me wish all will turn out alright tomorrow. I miss him. I miss us.

I will, for obvious reasons, not blog tomorrow. But I will ask each and everyone who carries Alec in their thoughts, hearts and mind, to think of him tomorrow at noon. I'll phone through an update to Heidi as soon as possible after we have received some news/answers/indications.

Until then blogland – Thanks for your help so far and thanks in advance for your help tomorrow.

Love

Pieter

Notes: That would be Alec’s last sip at something alcoholic.

And in hindsight, I am glad I gave it to him. His eyes looked at the glass so longingly; I could not help giving him a sip. And that sigh he gave when he swallowed it, will remain with me forever.

I was understandably upside down about the next day. What would the doctor say? Would he be able to help Alec? What if Alec needed to stay in hospital in Johannesburg? The whole day I had this feeling that I had to check the car – make sure everything was okay, check oil level and water. I decided to do it early the following morning.

RTS, Ramona and I had some email correspondence as well. It was decided that they would accompany me to the doctor. I was very happy about it.

From: Ramona
Sent: 18 March 2008 16:55
To: Pieter
Subject: Hello There

Hi Pieter and Alec
It was another crazy day here trying to wrap things up, and spent most of the day in Rosebank. Really tiring!

One thing we noticed, was that the traffic was a nightmare all the way to JHB due to the bad weather, so I'm guessing we should leave hear a little sooner than usual. Perhaps if you could be here around 10:30 or so?

I'm glad you're taking it easy.... we too are having a little glass of wine. I'm sure we're all pretty nervous about tomorrow, but I have a pretty good feeling about it.

I'm going to send you a map (RTS did it, and he thinks EVERYONE is an engineer!!) so it might be a little difficult to understand. So please call me when you get it so that I can explain it a bit better ... Although RTS thinks it's perfect, I wouldn't figure it out! (But I'm blonde!) :-)

We're really looking forward to seeing you.

Love

Ramona and RTS

From: Pieter
Sent: 18 March 2008 17:02

To: Ramona
Subject: RE: Hello There

Hi Ramona

Not wanting to get into your bad books, but perhaps it is a male thing? The map is PERFECT. 100% understandable.

Thanks for the map. Yeah, I figured we should leave here about 08:00, which should give us AMPLE time to get there.

I HAVE to be honest, and I am not going to fight it or succumb to it either – but I am scared about tomorrow. Perhaps scared is not the right word, but yeah, my nerves are a bit in tatters.

Anyways – see you in the morn
Love you both lots.
P

From: Ramona
Sent: 18 March 2008 18:30
To: Pieter
Subject: Map
Importance: High

Hi Pieter,

Attached please find a better map. I INSISTED that RTS re-do it! When you get on to J... street, just look out for a small little street to your right (L ..... street) We're the first on on the corner left, with a HUGE yellow wall & triple garage. If you do get lost just call us!

Have a peaceful evening both of you. (and Dad and Aunty M).

Sleep tight, tomorrow will be wonderful!

Love

Ramona

From: Pieter
Sent: 18 March 2008 19:33
To: Ramona
Subject: RE: Map

Dear Ramona

Thanks – love you to bits. You're so thorough. Thanks for going along tomorrow. Must admit – I am tired of worrying about Alec and its nice to know there will be someone to support me tomorrow.

Now for some (I hope) good news – another blade of grass. When I feed Alec, I always use a small towel as a bip (spelling). Just so that it is not food and spit everywhere. Well, today, when I gave his food to him, out of his own accord, he took the towel and put it ready for me! See, there are really a lot of small signs that point to the positive! I am just still very concerned about his fluid AND food intake. He eats very little and drinks even less and it does not matter WHAT I say, it just does not sink in.

See you on the morrow – we might be a little bit early, but then so what – longer time to spend with two special people in our lives.

Love (and to RTS too)

Pieter and Alec

It was very encouraging when Alec arranged the towel himself. To me, it showed that he also cared. But he was starting to eat less and less. In fact, I think it was on this day that he probably had his last solid food. From here onwards his food consisted of soup mainly and Ensure.

heidil here!

3:26PM, Wednesday, 19 Mar, 2008

I'm sitting at my desk, but I find I am unable to concentrate on my work. I keep checking the clock. 12h00 has come and gone, and it is now 14h30. I haven't heard anything from Pieter yet. What does this mean? I keep checking my cell phone – making sure I haven't accidentally set it to silent, or that it isn't playing its usual tricks on me and "hanging" … nope, its all in working order.

Maybe the doctor is running behind schedule, maybe he has sent Alec for a barrage of tests before he can make his diagnosis, or maybe Pieter left his phone at home by accident. All these thoughts spring to mind. I am concentrating on a positive diagnosis, that Alec's brain will be healed over time. But then that little devil jumps up on my shoulder and shouts loudly in my ear – "the diagnosis isn't good!" I shush him and carry on thinking positive thoughts. Alec *will* get better. Alec *will* get better. Alec *will* get better.

14h40 – check my phone again. Nothing. I smsed Pieter earlier – was afraid to phone him in case I disturbed. Alec *will* get better. Alec *will* get better.

14h45 – Alec *will* get better. Alec *will* get better. SMS from a fellow blogger – have you heard anything yet? Yip, my phone is definitely working ... SMS back, nope – not yet. To me this is a good sign!

15h00 Smoke break – make sure both phones are with me (work and personal). Positive thoughts as I sit in the garden and watch the butterflies playing.

15h15 – Pieter phoned! The diagnosis is not complete yet, and Alec will be seeing another specialist next week Tuesday, who will be able to confirm this specialist's diagnosis, before a treatment plan for Alec can be worked out. So they are on the right road to getting Alec better and that is very important. The specialist also mentioned to

Pieter that Alec’s recovery will be slow, and they both need to be patient.

Alec and Pieter send lots of love – they are driving back to Quiet Fountain now, and I am sure Pieter will do his own update when he has Alec settled in for the night. They want to thank you all for your thoughts, emails, comments, and most importantly for carrying them in your thoughts and prayers!

Right now, please keep your thoughts on them as they travel back – the weather up that way didn’t look too good when I looked at the weather forecast this morning.

To Pieter and Alec, I say "Kopf Hoch!" "Chin Up" – you are getting there and before you know it, Alec will be as right as rain!

Love you both!

Notes: What an exhausting day it was. I had had this nagging feeling the previous day to check the car. But I didn’t. I went into the garage early that morning and tried to start the car all to find that the car’s battery was flat. In fact, so flat that no lights even came on. Disaster! I did not have a Plan B. I phoned Annemarie to find out if I could borrow her car. Yes, I could, but how was I going to get myself and Alec to Potchefstroom? I phoned my church elder, who was on leave and who had said if ever I needed anything I should feel free to phone him. He agreed that he and his wife would take us to Potchefstroom and then we could drive from there to where RTS and Ramona stayed. From there they would take us to Milpark to see Dr F.

We arrived at their home at about 10:00. We had some time to have coffee. Alec enjoyed the trip so much. At a few minutes before 12:00 we walked into Dr F’s reception. Doctor was running behind schedule, we were told – we would have to wait at least 1.5 hours. Right in front of the Reception was another waiting area where we waited. RTS went to buy some coffee whilst Ramona and I kept Alec company. At this stage Alec dribbled a lot of spit, so I always carried a small towel along to wipe his face for him. He indicated that he also wanted coffee, but he could not even get in as much as a sip.

Eventually we went into the doctor's rooms, and I explained the whole situation to the doctor. What was refreshing was that he was prepared to listen to me and accepted me as Alec's life partner without any hesitation. Then he did some basic tests on Alec, which Alec kind of failed. Alec understood what the doctor wanted, but erred on the execution of the exercises he was given.

Dr F then concurred with the specialist at Tshepong, perhaps Alec did have PML. I then asked about prognosis, and soon discovered that Dr F was not really versed in HIV neurological diseases. In his defence – he is a very thorough doctor, but because the HIV neurological field is so different from main neurology, he suggested that rather I see Dr S and gave me his number. He then went on to explain that we had to remember that re-myelination takes time – giving at least a little bit of hope.

I phoned Dr S's rooms immediately, only to be told by the receptionist that Dr S did not accept new patients. So I explained to her that Dr F referred me upon which she put me through to Dr S. I explained the situation to him and then he said something to me which I will never forget – ever. "If your man has PML, it is imperative I see him as soon as possible". We scheduled an appointment with him for the Tuesday morning. We were lucky, because Dr S was fully booked for three months in advance. What was nice about Dr S's comment – he acknowledged Alec and me – there was no prejudice.

We started the drive back to RTS's home, and en route I went to task with the phone. Dr S needed a copy of Alec's records at Tshepong and I immediately phoned Dr H to find out what he thought the stance would be from Tshepong. I told him that Alec needed to see Dr S, and he explained to me that Dr S was the author of the book all doctors in South Africa use when it comes to HIV opportunistic diseases. That perked me up tremendously. He said he would find out for me what the hospital said, but he doubted they would release the records. RTS then said that he could get a lawyer friend to assist us in obtaining copies, at least.

Dr F gave a script for something, can't remember what, and upon arrival at their home, RTS dropped Ramona, Alec and myself and went to the pharmacy to fill the script – much to my distress, when I offered to pay for it RTS refused. Ramona and I sat down to a nice and welcome cup of coffee when I expressed my concern about Alec getting in enough nutrients. She suggested that I try Ensure. I thanked her and said I would get some the following day. Then Ramona said that she would get me some as soon as RTS got back from the pharmacy. I declined and said I could not expect her to get me some, I would purchase some. At this point Alec looked at me sternly, shook his head and said "uh-uh" – as if to say, don't argue with Ramona, and allow her to buy it. This had Ramona and me incredibly, incredibly enthusiastic.

We drove back to Potchefstroom to Annemarie's house where we picked her up and she brought us back home. By this time Alec was so exhausted, so when we arrived back home I immediately put Alec to bed. And then I had to explain everything we found out about to Dad and Martie. Dad sounded a little bit strange, but I shrugged it off as nothing. Then I emailed Ramona about Alec and Ensure:

From: Pieter
Sent: 19 March 2008 20:32
To: Ramona
Subject: Ensure.....
Importance: High

Hi guys

Just thought I'd let you know that the Ensure proves a huge success with Alec. Thanks for that bright spark idea. He had a full glass of chocolate this evening. Along with half a bottle of mineral water!!! Hallelujah!

I don't know how I will ever be able to thank you enough for all your care, love, support. Thanks for that.

Take care

Pieter

PS: I have not heard from my house doctor this afternoon so I will follow up in the morning with him at about 09:00 when he starts his day.

Will let you know latest 09:30.

Sleepies tight you wonderful people.

Friday AM

7:10AM, Thursday, 20 Mar, 2008

Morning bloglanders

I promise, I *really* wanted to do an update last night, *but*, you know how it goes with small town places and trips to the city. You have to tell the same story 10 times and answer a barrage of questions. And Alec was exhausted when we got back.

So. In a sense yesterday was a bit of a waste BUT in a much much bigger sense, yesterday was extremely successful. We arrived at the doctor's rooms with half an hour to spare and so the waiting began. Our appointment was for 12:00 and eventually he got to see us at 13:30. And we were in his rooms for over an hour!!!

Very nice and very thorough doctor *but* we discovered soon that as a layman, I had more knowledge on the diagnoses made on Alec than what the doctor had. I will not focus on the negative however, but rather focus on the positive:

Dr asked Alec to pick up his left arm. Alec did not. He lifted his right arm. This was not the result we wanted to see, No, *but*, Alec *did* know he had to lift an arm!!! So that is 50%, way better than 0%. We discussed the diagnoses that were made by the MTM hospital, and the Dr was of the opinion that under the circumstances the diagnoses were correct. However, when I started asking questions about prognosis etc., the doctor faltered and admitted that what Alec was diagnosed with, does not fall under his field of speciality and that perhaps it would be better just to confirm what he has said with a specialist in that very specific field. What he did however say was that we must remember that demyelination of the white matter can take place in a matter of days. Re-myelination takes much much longer and does not happen overnight, which is what I kind of thought. However, and this is where the miracle lies. Dr F said it might be a good idea to see Dr S. So he gave us Dr S's number.

I phoned Dr S's rooms from outside Dr F's rooms. Explained my situation to the receptionist who told me that Dr S does not accept any new patients. So I said that Dr F recommended we see him so she said, wait, I will put you through to Dr S. Spoke to Dr S, told him what Dr F said, told him what the possible diagnoses were, and of course that I am Alec's life partner. And Dr S answers: "If your man is possibly diagnosed with XYZ, I *have* to see him as soon as possible, we can not waste any time. Now I am fully booked for the next three months, *but* I will speak to my receptionist and see how soon we can fit you in." Upon which I was duly transferred to the receptionist who told me that we can see him on Tuesday AM. *Now*, the beauty of it all Dr S wrote the textbook GP's all over SA use at the moment when it comes to this particular disease.

Now how did Alec hold up? I will be honest – he was exhausted last night. A fairy told us yesterday that we should try Ensure. It is a balanced shake thingamajig. I was a bit cautious, knowing how Alec's fluid intake is and how difficult it is for him sometimes to take in fluids. *However* – BINGO!!! He had a full glass of which only about 15% wasted down the towel. The *much* needed rest landed in his tummy! Yippee. And yesterday he also had half a bottle of flavoured mineral water! And I dare say that I picked up a fighting spirit in Alec last night. He became very impatient about reading from the Bible – I could not do it soon enough. And whilst I read, he was completely at peace!

How did I hold up? I do not want to embroider too much about this. The urge is big, really big, to break my vows, *but* I will not. So concisely – God has led me on a road where He Himself showed me what angels look like. I am much more at ease with Alec and his condition. Much more positive than I was. And for *that* I say thank you. Yes, it is not easy. Yes, I have my moments too. In fact, I was so exhausted last night myself that at one stage I burst out in tears. But it was tears of exhaustion and not tears of despair. And afterwards I felt good again.

Today is going to be fun and games trying to get hold of Alec's records from the MTM hospital, which Dr S needs on Tuesday. But one lesson I learnt from our fairies, and so beautifully described by Heidil's email signature, the difference between Try and Triumph, is just a little Umph.

Then – *thank* you Heidi for yesterday's update. We really do appreciate it, you did it expertly as per usual. And lastly and most importantly, thank you to *you*, the reader and our friends, for your concerns, your support, your comments, your calls, your sms's. Without your support, we would not have been able to come this far in the process of getting Alec back.

Love

Pieter

Notes: Where I spoke of vows, I meant a promise I made to RTS and Ramona. A promise never to reveal their real names, and also not to blog about the assistance they were giving Alec and me. They said they were able to do it, and that should be enough for me. I have never seen generosity more in action. RTS and Ramona gave me a lot of pep-talks in those days. They were not only concerned about Alec’s well-being, but also mine.

On this day I also phoned Tshepong hospital and spoke to the Sister-in-Charge about Alec’s records. I explained to her why I needed them. She said she wished she could say yes, but because Alec was a state patient, his records belong to the state. Had Alec been a private patient, the records would have been no problem to provide. However, she said, Dr S was welcome to contact Alec’s specialist, who would gladly discuss Alec with him. With this information RTS and I decided that perhaps it would be the best route to follow.

Did my previous quote say Friday? Oops

10:45AM, Thursday, 20 Mar, 2008

Hiya

I guess I am getting confused with days now. Don't know why today feels like a Friday, perhaps because it is the last working day of the week? On that topic. Being self-employed, I deplore the idea of May 2 becoming a public holiday as well. It does not make sense. Monday 28 April – Public Holiday. Thursday 01 May – Public holiday. Friday 02 May, Public holiday. So by default it means that South Africa's economics comes to a grinding halt for that entire week. To me, that is counter productive and does not make economic sense at all.

Ok that's my only gripe. I know those gainfully receiving a salary will not complain about it in any case, and I suppose had I been in their shoes, I would not complain either.

Alec looks so much better this morning. Although still sleepy, we have already been in the garden and he has already had his morning fill of pills. Miesies Frog – many thanks for the suggestion about the bottle. I am however sad to report, Alec has Apaxia as one of the side-effects of his condition. That is the inability to move his jaws, chew and carry out related functions with the mouth, such as sucking on a bottle or a cigarette. Hence the reason why he does not smoke anymore. Therefore the bottle will not do. When I feed him, I make him sit upright and we take small small small sips at a time. It would have been ideal, were we able to use a bottle, but for now the glass will have to do.

lec finished a whole bowl of oats this morning. Good – that is more than what he had yesterday. And he already had half a glass of juice. All in all, all positive signs.

In a fit of creativity I rearranged the room and cleared the dressing table so that I can use that as an office desk. And moved my comfy highback into the room. Now I don't have to sit on the floor or on the bed anymore and work more productively, being with Alec all the time. Which makes me feel better too.

And that, dear blog friends, is that for the moment. Catch you all a bit later.

Love
Pieter

Notes: Alec looked very perky on this day – which made me feel positive. It was the first day this week that we were able to walk in the garden and he enjoyed it immensely. At one place in my garden, I had a pink rose bush. Alec stopped at this rose bush, touched a rose, and then picked it. He handed it to me, with a tear in his eye. He very often would pick me roses, but this one has so much more meaning to me.
I cannot for certain say when Alec stopped smoking. He had apaxia, which made his jaws clench and he was unable to control his lips. This is also why we could not get him to drink with a straw or from a bottle.

Moving my office into our bedroom also helped enormously with the guilt feelings I had for neglecting my businessin favour of Alec. It gave a false sense of security that at least I could do something about the business and being with Alec at the same time.

Thursday lunchtime

2:03PM, Thursday, 20 Mar, 2008

Guys, girls, friends

I am so excited. last night Alec had a glass of Ensure in two sittings. Today, with his lunchtime, he had a glass of Ensure in *one* sitting!! *Plus*, wait for this, his sips that he took were more controlled, meaning *less* spillage!!! Isn't it amazing?

When I told him how proud I am of him, tears just shot into his eyes. And *that* made *me* feel bad. Why, on earth, I haven't thought of it until one of our angels suggested it yesterday, is beyond me!!

All in all Alec is looking good today. What I did not mention earlier this morning, and what is of importance actually, the doctor pointed out that with Alec having received treatment for the second diagnosis, I must just remember that all of a sudden there are a lot of dead viruses in his bloodstream, that need to get out of his system. And that does take a certain amount of time and might also make him look worse than what he actually is. Having said that, we are not taking any chances and we are still taking him to Dr S on Tuesday. I'll rather be known for being overly concerned than not bothered.

Then, I was so wrapped up in my own sorrows and anxieties and whatever, that I very nearly forgot that it was Easter. And no, Easter to me is not an Easter bunny or Easter eggs and hot cross buns. No. it is for me about someone who died for me on a cross so that I could be free. And in that spirit, I wish *all* of you a very happy Easter, and I do hope that you will also think about Jesus dying on a cross for us.

And those that asked me to email my weekend updates (MissTiggerr and others), I would gladly do so, but do forgive me if don't remember it all the time.

Take care all.

Love
Pieter

Notes: At this stage there was such a huge following on Alec's illness, that some asked me to email my daily updates to their private email addresses so that they could access the updates from home, or rather on their cell phones. I tried to do it, but did not always find the time to do it.

From: Jessy. To: Uncle Alistair

3:14PM, Thursday, 20 Mar, 2008

Dear Uncle Alistair

Saturday is a very special day for you and your loved one, and Milo and I will think of you a lot, along with Daddy A and Daddy P.

I must just warn you though. These two photographs are proof of what happened to me shortly after my first wedding night.

Love
Jessy JR

Notes: Alistair Fairweather, Blogs administrator at 24.com blogs, had his wedding coming up on the Saturday, and Jessy tried to bring some light heartedness into the equation. Most bloggers on this day dedicated either a post or a comment to Alistair.

Scattergories

12:33AM, Friday, 21 Mar, 2008

Okay So I couldn't sleep and browsed the blogs ...
Scattergories – it's harder than it looks!
No joke. Use the first letter of your Blog name to answer each of the following.
They have to be real places, names, things – nothing made up.
You can not use your own Blog name for the boy/girl names.
1. Your Blog name: Jessy's Jungle
2. A four letter word: Jack
3. A vehicle: Jeep
4. A city: Jakarta
5. A boy's name: Jake
6. A girl's name: Julie
7. Drink: Jamaican Rum

8. An occupation: Jester
9. Something you wear: Jersey
10. A celebrity: Jake White
11. Food: Jam
12. Something found in a bathroom: Jasmine scented foambath
13. Something you shout: Jislaaik
14. An animal: Jackal
15. A body part: Jugular Vein
16. Word to describe yourself: Jubilant (well most of the time but not now)
If you are interested in the challenge……
Then leave a comment on Venus Goddess's blog – so that others can check out your blog
Copy 'n Paste this to your blog, change my answers to yours.
This could get very interesting!

Notes: I can't remember why I could not sleep that night, maybe because I was a bit upset. When this happened, I would spend my time reading other people's blogs. I particularly liked this challenge.

21 March 2007. I remember.

9:09AM, Friday, 21 Mar, 2008

Good morning

The heart is very sore today. My late mom would have been 63 today. She passed away aged 45. A stroke took her from us. When she had a stroke, I sat next to her bed almost 24/7. And as an avid Botany and Zoology student at the time, I could see how the spreading pressure and blood affected the various parts of her brain.

I have a certain sense of *de ja vu* with Alec. Though he is eating and drinking better, there are parts that I can see that get more and more affected. At the moment he has this very stricken face. Night before last I ascribed it to him just being tired after the long day. Not any more. He had ample opportunity to rest yesterday, which he did. But yet his face is still stricken, his mouth drawn in this awful shape as if he has swallowed something tasting very vile, his eyes sunken into their sockets. And he grinds his teeth to such an extent that I am scared they will break!! And no matter how much you warn him not to grind his teeth, it just continues.

I am confronted with the very real possibility of losing him, and it makes me irrational and extremely emotional. To the extent that I can just hold him and wet his back with my tears. I feel so powerless, so out of control. I had a night from hell, was up until 3:00 and then again from 6:00. When I get into bed, I catch myself watching Alec. If his breathing becomes too shallow, I start panicking, just to start crying of relief when he moves a foot, or takes a deeper breath.

I did however read up again on his condition last night, and in some cases they *have* reported a (temporary) severe deterioration which actually improves 2-6 weeks after onset. And while I know this should make me positive, I remember what I saw in '88 and whom I lost. And the saying goes, we learn from experiences. So forgive me for only being human, a very negative, down and despondent human today.

I know this is not what you guys wanted to read, but unfortunately, it is the reality I face.

Have a blessed day and please pray Alec and I have one too

Pieter

Notes: Ah, I remember what happened – Alec started to get this stricken look on his face. As if he had smelt something really bad, as if he was in a lot of pain, yet when you asked if he had pain, he shook his head. And the ever-grinding of his teeth – at stages I was scared that his teeth might break off. And no amount of gently asking him to stop grinding his teeth could stop him from doing so. Out of sheer frustration of being unable to help Alec I would cry. But that would not help either. When Mom had her stroke in 1988, I could see how and where the spreading blood affected her brain. With Alec I could see that too.

To make matters worse – it was my late mom's birthday on this day, and I am always emotional on 21 March. In 3 months' time, on the 21st of June, it would be Alec's 38th Birthday.

No subject

11:43AM, Friday, 21 Mar, 2008

Hi there

A copy and paste of how I am feeling right now. It is a Mariah Carey Song.

No, I can't forget this evening
Or your face as you were leaving
But I guess that's just the way this story goes,
You always smile ...
But in you eyes your sorrow shows
Yes it shows

No I can't forget tomorrow
When I think of all my sorrows
When I had you there but then I let you go
And now it's only fair that I should let you know
What you should know

I can't live
If living is without you
I can't live
I can't give anymore
Can't live
If living is without you
can't give,
I can't give anymore

Well, I can't forget this evening
Or your face as you were leaving
But I guess that's just the way this story goes,
You always smile
But in you eyes your sorrow shows

Yes it shows

can't live
If living is without you
I can't live
I can't give anymore
Can't live
If living is without you
I can't live,
I can't give anymore

Ohhhhhh(No can't live)
No no no (No I can't live)
I can't live (No can't live)
If living is without (No I can't live)
I can't live (No can't live)
I can't give anymore (No I can't live)

(Copied from http://www.lyrics007.com/Mariah%20Carey%20Lyrics/I%20Can't%20Live%20(If%20Living%20Is%20Without%20You)%20Lyrics.html)

Notes: Just the lyrics of a song that underscored my spirit that day. Seeing how Alec looked made me very, very sad. I realised at this stage that I needed a break from Alec – even if it was only for 10 minutes. So I asked my sister to come over for dinner. Okay, perhaps I am putting it wrong. I did not need a break from Alec; I needed a break from the situation we were in. I needed a break from Alec's condition.

Afternoon update – Friday 21 March

2:16PM, Friday, 21 Mar, 2008

Hi there
I am empty of tears – there are none left. I now only have a smile on my face and the wish that I could change places with Alec. He is hanging on nicely today. He had half a bowl of porridge this morning, a full glass of Ensure just now, a 1/4 of a glass of water in between, and he is scheduled for some slush puppy at about 15:00.

Sussa is coming for a visit – I asked her – so I'll be making roast chicken and the usual accompaniments for that. Decided I will purée some chicken, potato and brinjal for Alec for his dinner tonight. Adult Purity.

His face still has this stricken (I think the English word is gaunt) look but it is not as prominent as it was last night and this morning. I think the message of what I read last night again also finally sank in – the deterioration might be severe but it is reversible. I am banking on that now. I have to grab at every blade of grass I can get, no matter how much those blades of grass may cut my hands.

I also realise that I need some time-out from Alec, hence the reason I ordered Sis to come and visit. At the moment it looks as if I have dark-blue make-up on under my eyes.

On a lighter note – I am truly glad that Emmanuel and Lindsay won the Strictly Come Dancing season. They deserved it and they were my favourites from even before the season started. And of course Alec's too.

Shall try and give you an evening update. Thanks for carrying me today.

Love

Pieter

Notes: Ahhhh Alec thoroughly enjoyed Strictly Come Dancing the previous night. He enjoyed the series. It is hard to believe that when the series started, there was nothing (visibly) wrong with Alec. His speech was perfect, he was perfect; we were perfect, we were happy. And now, even though he had this gauntness in his face, even though he was gravely ill, he could still appreciate the dances and the competition. And he could still cry when Emmanuel and Lindsay won. He KNEW that they had won – he could UNDERSTAND that.

What is also important though, and I'll admit it, the realisation that Alec might have PML finally dawned on me. And I was grasping at every little sign I could get that would indicate the opposite – rather the demyelinating encephalitis. No matter HOW Alec deteriorated, I would find something that would point in the opposite direction. It was a roller coaster ride. From hell.

Saturday morning

10:02AM, Saturday, 22 Mar, 2008

Gooood morning

Yep. A good night's rest can work wonders. Though I did not take the sleeping tablet in the end. Why not? Well, it works like this. I packed the dishwasher and put it on and waited for it to finish its cycle so that I could switch it off. Whilst waiting Alec and I did our evening prayers and decided to watch a film, with Jessy lying on the bed. And Alec was lying in my arms and that is how we fell asleep. I woke up at about 01:00, quickly rushed to switch off the dishwasher, let Jessy out to the stoep and I got back into bed, snuggled in behind Alec's back and woke up again at 06:30 this morning.

The weather today is something incredible. Woke up to sunshine with all intentions of doing washing today, but that intention has now been washed away with the rain that started falling. Nice!!!

Alec had a good night. Had a whole Weetbix biscuit and his pills already and we are just chilling and taking it easy. Currently he is sitting up, as opposed to lying down. I just woke Sussa up with a cuppa coffee and all of us plan just to take the day as it comes.

Take care on this sensational Saturday

Love
Pieter

Notes: It was glorious falling asleep the way we did. Often, Alec would take his hand and stroke my face and look at me and smile, gauntness gone. And then he would just snuggle up in my arm, and fall asleep. Alec was a movies person. I am a reality person. Whilst Alec was ill and at home, I allowed him to watch his movies. When he was still healthy we could agree – now you can watch this and then I can watch that, but when he was ill, I allowed him to watch movies as much as he wanted. Only when he fell asleep and was sound asleep, would I change the channels to my programmes. And when he woke up, I would change back to the movie channel.

I remember the weather. As always, early in the morning I would open the curtains so that we could watch the garden outside. The sun was streaming into the house. But only half an hour later the clouds rolled in and it looked foggy and misty. And then the rain started. Whilst the sun was shining, Alec pointed to something with a smile on his face – a rock pigeon that nested in our garden, sitting on a branch of a fallen down tree I had placed in the garden.

Saturday afternoon

3:06PM, Saturday, 22 Mar, 2008

Hi there

O, what a blissful Saturday it is. Sussa woke up late and decided to stay an extra night. What bliss! She did however need to go home and fetch some clothes and feed the animals, so she kidnapped me. I fed Alec his strawberry Ensure, made sure he is comfortable and then set off with Sussa to go to her house and do what needs to be done. It did me the world of good to get out a bit, *but* at the same time I felt guilty about Alec being ensconced in bed. So, if the weather is a bit better tomorrow, we shall take him on a bit of a drive so that at least he too, has a change of scenery.

Yep, I have only been out of the house that day Alec went to the specialist, and I leave shopping to Dad. I only leave Alec's bedside when I need to do my chores, which is cooking and washing.

Upon our return I gave Alec some slush puppy, which he enjoyed. Grandma gave me feedback that Alec is in terrible pain, because of the way he pulls his mouth. That however is the apaxia he is suffering from at the moment – the inability to move his jaw, and that gives him this stricken gaunt look. Whenever I ask him if he has pain when he looks like that he says no – consistently. And I do the usual check and cross-check, so he can't lie to me.

Sussa is very supportive. It is strange – she hasn't seen Alec in a week and a half, and was surprised to see his deterioration, but at the same time also surprised at the amount of care Alec receives. Grandma only noticed now that Alec's mouth pulls the way it does, and she spends forever and a day in our room, and *still* insists it is pain. I left it left there. Reason I do not want to leave Alec alone for long periods of time is exactly that – I will have to leave him with Grandma, and as good as her intentions might be, I do not want him to succumb to her will. He does not need it now and I do not want to deal with consequences unasked for and offered in "good faith".

Sussa and I are now going to make macaroni and cheese and just spend the rest of the arvie on DSTV with Alec.

You guys and gals and friends take care.

Love
Pieter

Notes: It was good to be out that Saturday morning. We weren't away for long – if it was two hours, it was a lot. Practically we just went to my sister's house to feed her animals, and packed up some clothes for her, and whilst we were there, we had a whiskey and spoke about the situation at home. My sister had picked up the strange talking habit my Dad started to exhibit. He would stop in the middle of a sentence and forget what he wanted to say. He also lost the use of his right arm (which had polio when he was a child) and needed assistance when it came to slicing his food. This concerned my sister a lot. Yet Dad seemed otherwise fine. He was still full of jokes and did not give anything out to the outside world.

What I do remember about that day was that I really felt guilty not being at Alec's bedside. I desperately needed to be away from it, yet, I desperately needed to be there as well. I did not want him to feel deserted.

And I also did not want him to be subjected to Martie, whom we sometimes referred to as Nurse Martie, because she was a qualified Theatre Nurse, one who claims she knows more than any doctor alive. Alec and Martie had a love-hate relationship for a long time. When she needed something from Alec, like a tease or a perm, she pulled all the right strings, but any other time she just pretended he just did not exist and made hurtful remarks. Or she would say that she really liked what Alec did to her hair, and then two weeks later you find out from quite a different source how much she despised what Alec did to her hair. Alec was a qualified hair stylist with very little negative feedback and a very good clientèle.

Any case, I did not want to leave him for too long in her care – hence the guilty feeling. I knew he did not like her and she did not like him, and I had left him with her for two hours.

Upon our return she was full of the story that Alec was in pain. She kept on telling me how contorted his face was. I found it strange that she should only mention it on the Saturday. His face had been contorted for about 3-4 days already. She said he was in pain. No matter how hard I explained it was not pain, she would not budge. All tests and questions indicated that Alec was not in pain, all came out negative. Or perhaps I lived in a dream world. But I believe Alec would not lie to me. We could not lie to each other – no matter what.

RTS and Ramona were on their way to the Philippines on business. They had transferred an amount of money to my account in order to pay Dr S on the Tuesday. This is the email correspondence we had:

From: Ramona
Sent: 21 March 2008 22:26
To: Pieter
Subject: Sleep well!

My Dearest Pieter and Alec,

We read your blog, and although we are saddened by how you feel at times, we are overjoyed at the blades of grass Alec displays!

Our air tickets are only booked for Sunday as opposed to Saturday (yes, Ramona can be a tad "blonde" sometimes!)... So, we're NOT leaving tomorrow, which means we will be able to chat by phone tomorrow before we go.

Pieter, although we wont be here, please don't feel for a minute that we have abandoned You and Alec. We're only a phone call away, and we have arranged with our Mom (Terry) to take care of any financial need for Alec you may have. We know you're a very proud man, but lets focus on the "end result" for now.... that being the most amazing wedding the North West Province has ever seen!!!

We will call when we can, and will be in constant contact, by either blog or email. Please bear in mind that we have roaming on both our phones, and you can call us night or day.

Alec, my darling friend, over the months of reading your blog, I have grown to love you so much, and meeting you has been even better. Keep on smiling – you have a smile that can light up a whole room. Please stay strong for Pieter, he loves you so much – as you love him. Well done on the "Ensure"!! You and I had a great idea there!! Good luck for Tuesday's appointment, I just know it's going to be a step in the right direction towards your recovery.

I will call tomorrow, and I would also "telephonically" like to introduce you to my Mom. She's been crying/praying/loving for you both as long as I have. If by some chance you can't reach us, she'll be the one who'll be able to help you.

Sleep well, and please send all our love to Dad and Aunty M. -
Pieter please get some rest.

All our love & hugs,
RTS, Ramona & little ones.

From: Pieter
Sent: 22 March 2008 07:38
To: Ramona
Subject: RE: Sleep well!

Dear RTS, Ramona and little ones.

Many thanks for your email, we really appreciate it. Happy to say I had a good night's rest without taking the sleeping tablet. I think I was just so exhausted that my body just said SLEEP, BLISSFULL SLEEP.

Alec is still sleeping (at the time of typing this (07:29) but he had, from what I can pick up, a good night.

Glad to know that I am not the only one that have blonde moments sometimes. Thanks for all the re-assurances that you guys are there for us, and I promise this once, my pride is in my pocket and Alec has replaced my pride, in other words, getting him better.

I look forward to your call later on and meeting "mom". I also promise that I will send you an email once a day whilst you are away, as long as you promise that you will have a fabulous time whilst there. You deserve it.

I am sitting with a very pregnant Jessy on my lap. Very pregnant and very heavy, but so adorable and lovable. I dare say she became a bit cheeky now.

RTS, Ramona, words fail me, I am sorry. I just can not say thank you enough for what you are doing for Alec and myself. You are in our prayers, daily. I just pray that someday in the future I can be able to do for you what you do for us.

Many thanks

Love
Pieter (and Alec)

Sunday Morning

7:46AM, Sunday, 23 Mar, 2008

Morning morning

YASDIA. The sun is shining, not a breeze blowing through the leaves. And yet another good night's rest.

I have commissioned Sussa to take Dad and Aunty M out to lunch. There is enough macaroni and cheese left for me for today. It will do the two oldies good to get out of the house a bit – life does have the ability to go on. And Alec and I can do with some quiet time.

Jess spent the whole night with us in bed. It was as nice a treat for her as it was for us. Sussa brought her one dog along, and I just wanted to avoid conflict between the two bitches – at the moment Jess does justice to the title *bitch*.

Suppose I have to do some washing today since the sun is out.

Will catch you all a bit later.

Love
Pieter

Notes: YASDIA – Yet Another Stunning Day In Africa

Both my sister and I are early risers. I felt guilty because Alec got all my attention and Dad and Martie got none. So I asked my sister if she would mind taking Dad and Martie out to lunch to spoil them a bit. Dad objected to this because he could not use a knife because of his arm, so I reassured him that Joey would help him and that it was important to me that they got out of the house for a bit. Then Dad tried to get out of it again by asking what about me, and I reassured him that there was enough left-over macaroni and cheese for me to eat.

Sunday Afternoon

2:27PM, Sunday, 23 Mar, 2008

Hiya blog buddies

What bliss ... Alec and I have the *whole* house to ourselves. Okay, one would never say that it is a Sunday here, because I did one mega load of washing this morning. Whilst doing that the dishwasher was loaded too, and I cooked for the dogs. I fed Alec at about 1 p.m. and then we had our shower. Fitted the bed with clean linen, and the man is now happily snoring away.

Sussa and Dad and Aunty M are having lunch at the restaurant and I think I will reheat some mac and cheese shortly.

The *roller coaster* ride continues with Alec though, with moments where he looks terrible and moments he looks much better. But the general trend is better. He sits up more often now, and feeding is easier. On two occasions he came looking for me today, which I regard as a very positive sign. I have to point out here that what I am experiencing at the moment, I do not wish on *anybody*, including my worst enemy. It is *not* fun – and emotionally, physically and spiritually draining. However, I *have* to remain positive for both Alec's sake and mine.

I doubt I will post another post today – when Sussa comes back with Dad and Aunty M, I want to tackle her laptop and update her virus database for her. And besides, I want to spend some quality time with her, seeing that she came to my rescue this weekend.

Grab yourselves a stunning afternoon and once again, thanks for popping in to see how Alec is doing.

And remember – *love* your loved ones.

Love
Pieter

Notes: It was utter bliss having the home to ourselves. Alec and I had a long shower and just held on to each other. Afterwards we just lay on the bed together, feeling in love and happy, despite Alec's illness.

After Joey returned with Dad and Martie, I asked her if she would mind taking us for a drive, so that Alec too could have a change of scenery. Alec got to sit in the front seat and seemed amazed by the changing scenes. Little did we know it would be our last ride together with him being out of hospital that day.

The next two would be in ambulances.

Dear Riatsila

9:21PM, Sunday, 23 Mar, 2008

I am not here to convert you. I am not here to question your intentions. I am not here to judge you.

I am however entitled to say what I do *not* wish you, I am sure about that. And this is what I do not wish you:

I do not wish you to lose someone *so* close to you. This world allows you to have a special person, whether it is a man or a woman. I wish you would never be in a situation where you have to feed said person because he/she is unable to do it themselves. I wish that you would be spared the duty to help such a person in the toilet. I wish you are spared the sight of such a person withering away, becoming a living skeleton to such an extent that you don't know whether he/she will be alive when you wake up, when eventually you do drift off to sleep. I wish for you that you will never have to feed said loved one, where it takes you 45 minutes for him/her to take in 250ml of fluid. I wish for you that you will never have to endure said person "getting rid" of 125ml of that fluid. I wish for you not to lose a loved one. And I know, deep inside, you do have one. Be it a father, a mother, a girlfriend / boyfriend. I wish for you, that should you ever get into a situation like mine, you have the unconditional, loving support from a community that only knows how to love. A community that only knows how to give support – without questions asked. A community that will not chastise you for getting the Anaconda and the Cobra wrong in terms of Ratanga Junction and Gold Reef City, but one that would instead read "Roller Coaster Ride", and love you for the mistake. I wish for you that you would not have to endure, day for day, minute for minute, seeing someone melt away, disappearing in front of your eyes, and that you have this helpless feeling of not knowing what to do. *No*-one deserves it.

See Riatsila (by the way, my name is Pieter, in real life), I am in a situation where my life partner IS gravely ill. In fact, and I do not want to sound negative, I am not sure that he will see the end of this week. It is *reality*, not fiction. I have to feed the person I love with all my heart. It takes me 45 minutes at least, per sitting. I have to tend to his ablutions. I have to see him wither away. I have to see how he looks at me with skeletal features as if he does not recognize me, as if I am a stranger. I have to see him day in and day out, unable to eat. Unable to swallow. I have to see him looking like a dead man before I go to sleep, not sure that I would see him alive when I wake up. Because even I have to sleep. Some time.

You take car,e my friend, because inherently, I believe, every one has good in them. Irrespective if they believe in God or not. I am not to judge. Just to give care.

Love
Pieter

Notes: 99.9% of all the comments on my blog posts were ones of concern, supportive in nature, or just giving me encouragement.

One blogger posted a very negative post on his own blog about Alec and myself and our situation, and I happened to see it. I was extremely hurt, and my first reaction was to lash out against this person. However, I sat down and thought about what Jesus would do, and decided to rather write this post. I came from my heart and evoked plenty of congratulatory comments. But deep inside I was torn and angry and if I could have found this blogger at that stage, I would probably have done him or her physical harm.

The strange thing is – the blogger never apologised about the post he wrote. However, he did stop leaving hurtful comments on my blog posts, and started leaving inspirational quotes from that day on, until he removed his blog of his own accord. That to me was apology enough. He returned later under a different blog name and we actually became blog friends.

I did not; however, share this negative experience with Alec.

Monday Monday

8:44AM, Monday, 24 Mar, 2008

Good morning all

Had a rather bad night – good not fall asleep until well after 3, up again at 05:30.
Alec is doing okay though – just very restless – moves around a lot, sitting upright, then lying down, then sitting upright again. He is due to have his morning feed. Hope it goes well.
Jess is also getting very uncomfortable now – and snores like a beast when eventually she sleeps. I'm guessing she will have 5 babies. Don't know why, just a feeling. She is due in about a weeks time.
Sussa is sleeping in a bit. I will wake her at about 10:00, if she is still sleeping then.
And that is about it.
Have a miraculous Monday.

Love
Pieter

Notes: I guess I had a restless night because of the Riatsila post. My mind was mulling with the thoughts of why anyone would want to attack someone who already had enough on his plate. What type of person could that be?

Alec was also very restless. He had these spastic movements: rolling from one side of the bed to the other, then sitting up, then lying down again, then turning his head this way then the other. Eventually he fell into a deep sleep and the movements calmed down, and then I was able to sleep as well.

I'm feeling very small

1:36 pm, Monday, 24 Mar, 2008

Hi there

Idiot! Dumb *twat*! Poepol! That is what I keep on telling myself. Why? Because I battled so long to get Alec to drink something without spilling anything. And how did I solve it?

Ye old disposable syringe (without the needle of course). 250mls now takes 5 minutes to give to Alec with *zero* spillage as opposed to 45 minutes with about 10% spillage. And our boy looks relieved too. It is not a big syringe – takes 5ml at a time and it works wonders. It also means I can now start giving him Pronutro in milk. And I will be able to give him some soup this evening. Okay, I'll have to pass it through a sieve first, but that is okay.

Tomorrow by this time we should have some answers already, I hope. We're hitting the road at 05:00 already in order to allow time for traffic congestion, etc. Have no idea what time we will be back. One of my friends and his wife offered to take us through to Johannesburg, so that I can concentrate on Alec in the car. Thanks Peter and Magda.

And then I'll ask Heidi to do an update once we have been to the doctor.

And *maybe* I will do an update a bit later.

Love
Pieter

Notes: Feeding Alec was my biggest concern at this point. It took forever to get him to drink from a cup, and about half of what he should have taken in ended up on the towel. I was very worried about him becoming malnourished, and I constantly thought of ideas to make things easier for Alec. When the idea of a syringe struck me, I immediately tried it out and it worked! I was over the moon, in fact I was ecstatic! And I could see a measure of relief on Alec's face too.

Because Alec at this stage was a handful and very prone to involuntary movements, Peter and Magda offered to drive us through to Edenvale to see Doctor S, so that I could concentrate all my energies on Alec in the vehicle.

I had also told Dad that I was going to take him to the doctor on the Wednesday so that he could be examined. For once Dad did not argue with me – normally when I told Dad to go to the doctor, there was this huge argument about why it was not necessary.

Monday night

8:05PM, Monday, 24 Mar, 2008

Hiya blog buddies

The syringe works wonders *but* I think I will invest in a feeding syringe tomorrow – thanks Hutton and Liz for the suggestions. I am happy with Alec's fluid and food intake for today.

Three small little gestures this afternoon give me a ray of hope. Shortly after the first successful glass of Ensure Alec actually took me in his arms and gave me a hug, as if to say, "Thank you for finally discovering the syringe – what took you so long!"

Second one – we were watching Extreme Makeover and something happened that irritated Alec immensely. So much so that he waved the people away with his hand – as if to say "Just disappear, won't you". Now this is something the old Alec typically would do.

Third one – on more than one occasion today, if for some reason I was out of the room too long, Alec came looking for me. Something that surprised me and encourages me immensely.

Then I owe a thank you to all who have responded so positively to my open letter to Riatsila. It was encouraging to see that I am not alone in this thing. And to tell the honest truth – I did not expect Alec to wake up this morning. No, I am not negative and no, I am not expecting the worst, *but* he was real bad last night and most of the morning, but there seems to be a miraculous improvement.

Well, we are all set for tomorrow's visit to the doctor and we hope to have some clarity and sense of direction at the end of the day. You all sleep well, I still have to finish two quotes I promised my clients to have tomorrow whilst I am away.

Love
Pieter

Notes: In these last days of Alec being at home, he became very dependent on me. If I were out of our room for too long, he would come looking for me. I chose to see this as a positive sign. We walked in the garden often. Alec's fluid intake increased remarkably due to the syringe.

When Alec was still healthy, he had this "waving someone away" gesture if something annoyed him on television. Both of us had this pet hate – the use of the words "Oh my God". To us it was extremely blasphemous. We were watching Extreme Makeover Home Edition when one of the contestants used the phrase too excessively and Alec exhibited that waving away gesture. It encouraged me a lot, because it showed me that he understood what was said.

A third thing that perked me up tremendously that day, was that Alec gave me this big hug and wet sloppy kiss after switching to the syringe. It was as if he wanted to say thanks.

My email correspondence with RTS and Ramona:

----- Original Message -----
From: Pieter
To: Ramona
Sent: Monday, March 24, 2008 2:28 PM
Subject: Glad to see you arrived safely

Hi there RTS and Ramona and littlest ones

As you read I have made a bit of progress – not necessary for the feeding tube tomorrow. A much more convenient solution presented itself to me – the common syringe. Makes life for Alec and myself soooo much easier, and now I can feed him more too. We have already doubled the fluid intake from yesterday. I just feel stupid that I had not thought of it earlier.

This roller coaster ride is becoming hectic now, BUT we are on a high today, well at least I am. Alec gave me a hug out of his own, which to me was so special!!!

Regarding tomorrow – you'll be able to read about Alec before I am back in Stilfontein because Heidi will do an update, but perhaps I will sommer phone you. Too lazy to look up, but how far ahead or behind are you from us? Do not want to phone you in the middle of the night.

Take care and love, as always
Pieter

From: Ramona
Sent: 24 March 2008 14:53
To: Pieter
Subject: Re: Glad to see you arrived safely

Ah Pieter, we learn as we go along! You're doing a magnificent job taking care of Alec! When he's all better we're going to have to treat you to no end!! I'm so pleased that your friends are taking you through to JHB tomorrow, I was so worried about you having to go through on your own.

Please do call us at ANY time! Even SMS will do. I have a good feeling about Dr. S. And PLEASE! Do what you have to do, and call my mom at anytime if they need to do more tests. If you have to do it right there and then, call me immediately so that I can give them my credit card number. Okay?

By the way, I picked up that you had some trouble with Insults on your blog. You handled it VERY well, although I didn't see what he had to say. RTS was livid!!! He says just wait until ridetheslide gets back!!!! LOL He was hopping mad!

Love
Ramona

PS My cell number is XXX XXX XXXX
XXX

From: Pieter
Sent: 24 March 2008 15:01
To: Ramona
Subject: RE: Glad to see you arrived safely

Promise Ramona.

The dumb twat made a very derogatory post saying we are attention seekers and should get on with our lives. I see he has removed the post though. Just thought I'd put him straight.

Will let you know about the money in Dad's account as soon as I have checked, but thanks so long for that.

Enjoy your time

Love,
Pieter

Please keep Alec and Pieter in your thoughts & Prayers – heidil

8:25AM, Tuesday, 25 Mar, 2008

Morning everyone

With Pieter (and Jessy's) permission, I have blogjacked his blog this morning! I am entrusted to do an update later once Alec has been to see the specialist, but this blogjacking is to ask each one of you to please keep Alec and Pieter in your thoughts today – especially from 09h30 when the appointment with the specialist is scheduled.

I am positive that this specialist will be able to put Alec on the road to recovery, and will also be able to give Pieter the information and knowledge as to how to care for Alec, and his special needs.

As soon as I have any news, I will do an update.

Thank you all for supporting these two very brave men.

Notes: We were already in the car en route to Edenvale when Heidi posted this.

Our nerves were a bit shot. But we were coping. Alec was very calm in the car. Though I had a fair idea where Dr S's rooms were, (well the general area anyway), we did end up going in the wrong direction, but quickly realised our mistake. I was happy to see that day, that I was not the only one who got nervous in the Johannesburg traffic, even though I lived there for over 10 years and had endured it daily. It was very evident that Peter did not like driving in Johannesburg traffic at peak hours either!

Light at the end of the Tunnel – heidil

11:23AM, Tuesday, 25 Mar, 2008

The best news so far, and I am so happy and excited to write this update!

Alec is going to be fine!!! He is going to get better! It is going to take from 2 to 3 months for him to make a recovery, and this will take patience, and perseverance as the progress will be slow. His specialist suspects that he is suffering from DE (Demylienating (I think I spelled this right) Encephalitis), and once he has been in touch with the MTM hospital doctor, under whose care Alec is, he will be able to confirm this. As far as the specialist is concerned Alec is not suffering from PML (Progressive Multifocal Leukoencephalitis), which is such a relief, as this is the disease for which there is no known cure as yet. Alec's vital stats are all perfect!

The specialist has commended Pieter on the care he is taking of Alec, and has said that he is doing everything right to ensure that Alec recovers. He has changed Alec's medication slightly. Pieter will be phoning him on Thursday to get a full report once the specialist has caucussed with Alec's MTM doctor.

I cannot tell you how relieved I am! This nightmare our friends find themselves in will soon be something of the past!

We need to keep them in our thoughts and prayers, as Pieter especially is going to need the patience to deal with Alec's needs daily. Once again I appeal to anyone who has any ideas for helping Alec get back on his feet again. No matter how small or silly it may seem to you, it could have a significant impact on their lives – for instance the syringe that Pieter has only just recently discovered which helps him to feed Alec more easily. We need to think of ways to keep Alec stimulated and his brain active, which will help speed up the recovery process.

Once again Pieter has asked me to thank everyone for their valuable input and their prayers. Without you, he and Alec would never have made it thus far. Your comments and emails, telephone calls, faxes and sms'es are what keep him going, what keep him positive, and what is making a difference in their lives.

I take my hat off to Pieter and salute him – he has shown me the power of true love – at a time when I have become very cynical.

They are on their way back to Quiet Fountain now, and I am sure that Pieter will do an update as soon as he has Alec settled, and he has told Oupa and Aunty M the good news.

Notes: All in all, our visit to Dr S went extremely well.

I remember that while sitting in the waiting room to see Dr S, Alec needed to use the bathroom. Poor Alec was so confused between the toilet and the hand basin, so I had to help him. I needed to unbutton his fly for him and button it up again after he finished, and then I had to help him wash his hands.

Dr S told me that he doubted Alec had PML, as he had seen enough PML patients in his life to know what a PML patient looks like. However, he first wanted to speak to Alec's specialist at Tshepong, as there were pertinent questions to be asked before he made a final diagnosis. Dr S put a call through to Tshepong to speak to Alec's specialist, but unfortunately he was out of town and on his way to Gauteng for a meeting.

So Dr S and I had a lengthy discussion on how best to treat Alec. What I found so refreshing was that Dr S was such a kind and caring man, he really showed empathy and I felt that Alec was in good hands. We spoke about Demyelinating Encephalitis and Dr S said that if that was what Alec had, he would be at his worst then and that from there on onwards we would only see an improvement. This lifted my spirits up immensely. I also asked Dr S if it was okay if I ground up Alec's medication, mixed it with a little water and then injected it into his mouth and Dr S said this was an excellent idea

I was to contact Dr S again on the Thursday to hear if he had heard anything back from Alec's specialist in Tshepong.

We left Edenvale in high spirits for the two and a half hour journey back to Stilfontein. About halfway, at Fochville, we stopped for a juice and a smoke break. Alec was visibly upset because I left him in the car with Peter and Magda whilst running in to the shop to buy the juice.

Ok – back home!!

2:08PM, Tuesday, 25 Mar, 2008

Hi there blog buddies

These past few weeks have been nothing less than *hell* for me and Alec. I am glad to say it is *nearly* over. HeidiL – *thanks* – you did a splendid job.

Now, my version and I'll be quick. The Doctor said Alec is too healthy to have PML. Period. He *is* the doctor that wrote the textbook other doctors use in treating these kind of diseases. You don't write a textbook if you have not seen a fair number of patients. You cannot express yourself on a matter if you do not have sufficient proof and suitable qualifications and experience. Period.

He says Alec has DE *and* that the disease is taking its normal course. Just like a flu. You are going to sneeze, you are going to produce a lot of phlegm. Same with DE – your body will deteriorate *but* it will get better and better. He reckons Alec is at his worst now.

He is, however, going to liaise with the MTM Hospital re Alec. Especially in regards to the treatment he is currently on. They have prescribed a cortisone, which according to the specialist we saw today, is about double the dosage he should get – and which could very well be the reason why Alec is so non-responsive and comatose. The specialist said he would have prescribed 30mg per day for a two week period *max*. Alec was on 60mg for four weeks!!! He asked that I stop that pill immediately.

After a thorough examination he declared Alec's reflexes normal and perfect. Another good indication that Alec's condition is on the up, even though he looks very bad at the moment.

I discussed with Alec's specialist how and what I feed him and he is very happy with the regimen.

Now – I want to vent, if I may. I *have* to get rid of *some* anger. *Why* is it that at the MTM hospital the doctors would not speak to me and actually treated me like a syphilis/gonorrhoea patient when it came to matters concerning Alec? Why could both the specialist we saw last week Wednesday and the one today, talk to me open-heartedly with genuine concern and empathy? What makes them different? Even if it is the last thing I do, I *will* work my friggen arse off so that Alec and I can afford a Medical Aid Fund, so that should something like this ever happen again, we do not have to deal with an MTM hospital. Look, I take my hat off to them, I am sure they deal with a lot. But empathy and caregiver empowerment lacks sorely! Having said that, I am still grateful they did help Alec.

And that, my dear friends, is that. I'll be honest, I had two nights in a row where I expected the worst. I guess its only human. And one feels so so powerless.

But now, we can focus our energies on getting my miracle man better. The North West is waiting for the best gay wedding for 2008 (as two of my very dear friends would say)!!!

Love
Pieter

Notes: The MTM Hospital I refer to was Tshepong Hospital. I did not want to call it by name in the blogposts out fear of discrimination against Alec, should one of the doctor's there perhaps be a blogger. What I did find amazing about my discussion with Dr. S was that there was none of this “but you are not family” nonsense that I experienced at Tshepong. They were always so guarded with what they said to you there.

On our way back I tried phoning RTS and Ramona to give them the news. They were somewhere in the Philippines on business. I could not get through to them, so I sent them an SMS, after which they phoned me back immediately. They were ecstatic at the news of Dr S's opinion.

Upon arrival at home, I immediately fed Alec and left him to rest.

Dad's speech had become affected quite badly all of a sudden. His sentences were shorter – he would start a sentence, say two words, and then stop. It was as if he could not remember what he wanted to say. I tried to see if I could get an earlier appointment with his GP for him, but none was available. I had no idea what was going on with Dad.

I went to the pharmacy a bit later to buy a bigger syringe with which to feed Alec.

My email correspondence with RTS and Ramona, that day:

From: Ramona
Sent: 25 March 2008 13:19
To: Pieter
Subject: Babbling ME!

Hi Pieter,

I was so overjoyed at your wonderful news, I hope you didn't think I was babbling!! LOL

I still haven't told RTS, he's still in a meeting, but he must have called about 10 times before you called to find out if I had any news.

So I guess after you've spoken to the doctor on Thursday you'll know more about how to handle Alec's recovery. Please bear in mind the Occupational Therapist's details that I emailed you some time ago. When both you and Alec feel up to it, please just let me know. We would go to the end of the Earth to see him recover 100%.

I'm sure you're going to sleep much better tonight. It must be such a relief to you both just to KNOW it's going to be okay. You both remain in our thoughts and prayers.

Please send all our love and hugs to Dad, Aunty M, Jessy ... and don't forget Milo!!

Love
Ramona

From: Pieter
Sent: 25 March 2008 14:17
To: Ramona
Subject: RE: Babbling ME!

Hi Ramona
I am overjoyed!!

No you did not babble at all – remember, you both are in this with me, are you not?

We will certainly bear the OT in mind – but now we only need to be patient so that this virus can have it's last few days with Alec before he starts getting better.

Dad and Aunty M send their love too. And Milo and Jess. Have to take Dad to the doctor tomorrow – he lost all sensation in his right arm and his speech is slightly affected. I suspect a small, minute stroke, but we'll see what the doctor says tomorrow.
Love
Pieter

Just a short post

8:24PM, Tuesday, 25 Mar, 2008

to say THANK YOU.

And to say – WE love YOU

Pieter (and Alec by default)

Notes: We were so overwhelmed by everyone wishing us well and standing by us that I just had to write this post.

Wednesday morning

8:26AM, Wednesday, 26 Mar, 2008

Good morning blog friends

What a sunny morning. Sure the day will turn out just fine.

Although I did have a better night than the previous two, it was still filled with a very restless Alec – tossing and turning and pulling the duvet off me, then putting the duvet back. *But* I am not complaining, it means he is on the mend. Which leads me to ask, actually beg. Once Alec is better, he and he takes to blogging again, please please please do not overwhelm him with messages of how lucky he is to have me or that he gave us a great fright or something like that. Rather just welcome him back and tell him that it is good to see him again, do not dwell into his illness. There is a very good reason for this request – that of Post Traumatic Stress Disorder. By making the first class of comments, it could psychologically create a depression, which is the exact opposite of what we want to achieve. We want him to come out of this and hopefully he will not have to deal with the stresses of what he had to endure. At the moment I am actually asking everyone who gets in contact with him not to mention work for instance. Just because it could trigger an anxiety attack with him. Perhaps I am an over-protective old cow, I don't know, but I have read somewhere that one should avoid the things I mentioned. Later on, when Alec has come to the realisation of what has happened to him, he will talk out of his own accord – and that is the type of healing process we are hoping for.

Then, today, sadly I have to take Dad to the doctor. This thing with Alec has taken its toll on everyone. I was very despondent at stages. Tired, worried. And in return Dad was very worried about his son. So much so that he lost sensation in his right arm and that his speech became affected. Not badly, just mildly, but sometimes he would stop mid-sentence forgetting what he wanted to say. I suspect it was a very small stroke and that Dr H will be able to sort it out.

Then – it was suggested by someone that we have ourselves a little guess competition in regards to Jessy's imminent litter. So here is the guess:

On which day is Jessy going to give birth and how many babies is she going to have?

My guess, and I do not know why, would be that she is going to deliver me a whole bunch of April Fool's babies – five of them. What do you say?

Take care and love each other.

Love
Pieter

Notes: Even at this advanced stage of Alec's illness, he was very aware of me. The involuntary rolling around and the pulling off of duvets would continue for about two or so hours and then he would settle down, either with him lying in my arms, or on his side with his arm over my chest.
I was very confident that Alec was on the mend, and was now more concerned about his psychological well-being once he recovered from his illness, hence the request in my blog post.

His employers were on my case daily – requesting updates, feedback and wanting to come and visit Alec. When I asked him if he was comfortable with them coming over he was visibly upset and just shook his head. So I told them that it might not be a good idea to see Alec as it would upset both them and him. At this stage I had still not informed them that he was HIV+ and when they wanted to go into details about the two possible conditions he might have, I played it down and just gave them the necessary information, leaving out bits that pointed to HIV.

Wednesday mid-morning

10:37AM, Wednesday, 26 Mar, 2008

Hi there blogland

I have just been to the doctor with Dad. On our way, walking to the doctor's rooms, I noticed that Dad's gait was also affected, in that his right foot catches when he walks. This confirmed a small stroke to me and the Doctor said I am spot on. We now have to prevent a major stroke.

Dad's pulse is very high and Dr prescribed something for it. I am on my way to the pharmacy to get that pill. He also gave Dad something for his nerves as I believe that it is his anxiety about me and Alec that brought the stroke on in the first place.

I am now however faced with a dilemma. I have to look after not only Dad, but Alec as well. I have to run a business, I have to prepare all the food in the house, do all the washing, etc. I am only one person. I therefore summoned Sussa for dinner tonight so that we can discuss ways and means for her to get involved. I have to. For instance, Dad has got something in his eye that could, if we do not intervene now, lead to a cataract developing, and therefore impair his eyesight. He needs to see a specialist for that, and that means someone has to take him. Sussa will have to step in. I am now taking control of our family. Not an easy thing to do, but it needs to be done.

I will also, as from today, not blog as often anymore. I will try my utmost best to do an update in the evenings, but I am afraid, that will be it.

You guys and girls take care. And as always, remember, *love* your loved ones.

Love
Pieter

Notes: I felt completely overwhelmed this day. It was as if the carpet had been pulled out from under me.

Dr H did not think Dad's stroke was that severe but ordered that he be kept very quiet and calm. He prescribed the same tranquilizer I was using for Dad, as well as another pill to bring Dad's pulse and blood pressure down. Thankfully Martie being a retired theatre nurse and who monitored her own blood pressure regularly was now tasked to monitor Dad's blood pressure as well.

I now also sat with a dilemma: Dad had to see an eye specialist and I was unable to take him, as I could not leave Alec alone for one second. He took it badly when I told him Dad had had a small stroke. I was quick to add that Dad would recover quickly. I could not show Alec my concerns, out of fear that it would unsettle him, and I did not want to add to his burden. So I phoned my sister and called a family meeting that night. I explained the situation to her, and why I needed help desperately. She agreed to take Dad to the hospital the following day to see the eye specialist.

My e-mail correspondence with RTS and Ramona on this day:

From: Pieter
Sent: 26 March 2008 15:20
To: Ramona
Subject: Alec Progress

Hi guys

Thanks so much for the nice tribute you did last night on RTS's blog. Really nice and it left a lump in my throat and a tear in my eye.

Alec is doing indeed much better today – I think that pill we dropped has had a serious effect on him. He already had a glass of Pronutro with milk (very thin so I can use the syringe, 2 glasses of juice, 1 glass of water and 1 glass of Ensure. The improvement is in his reactions – he is like a small baby at the moment, trying to explore all that happens to him. And very touching – he can not touch me enough, holding on to my arm, etc.

I have however received some bad news today about Dad. He suffered a minor stroke and I have to keep him calm and sedated to prevent a second (major) one. Doctor has given him something to bring his BP down as well as his pulse, which were sky high, and about an hour after I administered the pill, we could see his pulse went down from 120 to 72. So here's to holding thumbs.

I summoned Sussa (want you to meet her some time) and explained to her that I am one person and only one person, and that she will have to step in and help. Seems as if she is coming to the realisation I wanted her to have, and as if she will indeed help.

Anycase, just wanted to give you feedback. Take care and hear from you soon.

Love
Pieter

"I will survive" – Gloria Gaynor

8:55PM, Wednesday, 26 Mar, 2008

Hi there

The popular song by Gloria Gaynor rings through my mind at the moment. What is important though, is the part where it says – *I will survive*. And so will the two men in my life – Alec, and my dad.

Alec is constantly showing signs of improvement now. When I feed him (I invested in a bigger tube) he takes it in both his hands, looks at it, and then puts it in his mouth. Very much the same as a baby would do. Whenever I get close to him, he becomes "clingy" – of his own accord. Which is nice. It shows me that he wants me near him. And I dare say that the improvement is due to the one pill we stopped on the specialist's advice.

Sussa was in a panic today. She went through the 5 phases of acceptance so quickly – first denial, then anger, then self pity and then she took control of it and then offered her support. She is taking Dad to hospital tomorrow to see the eye specialist. Thank you, thank you, thank you.

Dad is very impatient and quite frankly very stubborn. *But*, he does listen though. I suggested the aid of a walking stick today and he said he would think about it; next minute I see him walking with the walking stick. Suggested that he should not feel embarrassed to ask for help in the loo (I mean he has to undo zips and buttons and that with only one hand) and there, Dad asks for it. *But* don't go and faff over him – he can't stand it. I think I take after him. If I am sick, leave me alone. I'll get better. I'm glad to report however that we managed to get both his blood pressure and his pulse down with the additional meds Dr H prescribed. His BP dropped to 147/88 (which is neat for his age) and his pulse from 120 this morning to 78 this evening. Okay it is only day one, but all indications are that it seems to be working. And he did not complain about any adverse side effects – yet. But then, he would not.

I am exhausted now though, and am going to fall down in bed. I firmly believe that from here on, things can only go better!!!

You guys and galls take care. And do not forget our little guessing competition – when is Jess going to have babies and how many is she going to have.

Love and take care
Pieter

Notes: Dad was never patient when he was ill. According to him there was nothing wrong with him. And the more Martie told him to take it easy the more he became annoyed with her. And then she would come and complain to me about this. I would tell her that almost all stroke patients were short tempered and then she said something like, "but not the ones I worked with".

I discovered how to handle Dad some years ago and found that if I wanted him to do something it would be best to suggest he do it, not tell him to do it or ask him to do it. I would phrase a suggestion as follows: "Dad, don't you think it would perhaps be better if ..." Doing it this way around empowered him to think things over and make the decision to do it himself. And 99 out of a 100 times he would go with my suggestion. But if I told him outright to do something, he just would not do it.

Alec became very clingy. Whenever I was near, him, he grabbed my arm. When I fed him, he grabbed my wrist or the syringe and guided it to his mouth. His food intake was good still, and I regarded all these as positive signs.

Oooh hoo – Fun and Games!!

8:04AM, Thursday, 27 Mar, 2008

Hi there, blog buddies

I have couple of hours sort of for myself at the moment. Sussa just picked Dad up to take him to the hospital. Living with a stroke patient is going to be fun and games, it seems. It is a well known fact that people who have suffered from a stroke become extremely irritable and impatient. And Dad is no exception. And what aggravates the matter even further is that Dad does not like it when people faff over him when he is ill. And to Grandma it comes naturally, and then she cannot understand it if Dad is impatient with her and her feelings get hurt. Now, (not complaining), I have no schooling in the medical field, but I know this. She is a qualified theatre nurse with countless doctors as friends (she says) and she does not know this. Oi ...

Alec was extremely restless again last night, and it continued this morning. But I take that in my stride. I have considered sleeping in the guest room, but I am scared that he wakes up, finds that I'm not there, and then feels rejected. So I rather sleep in our bed with him and take it in my stride. Today I am going to try the use of a baby bottle to see if Alec takes to that.

I am going to try and catch up on work. So I'll see you all a bit later.

Oh yes – couple of things, actually. Thanks to those who have emailed me with offers of help – being prepared to drive through to come and help me. I will most certainly make use of your offer when the need arises. Also for Kosmos who offered me a liquidiser – I never thought of that and mine will come in quite handy.

And thanks once again for all your messages of support and keeping us in your thoughts.

Love
Pieter

Notes: The title of this blog post was a bit sarcastic and more aimed at Martie than at the situation. She again complained bitterly about Dad not wanting to do what she told him to do – and then she came and took it out on me.

Alec's restlessness increased nightly, to such an extent that I even considered sleeping in the guest room. But I could not do it out of fear that Alec might wake up in the middle of the night, come looking for me and not knowing where to look, would feel rejected or discarded. Something like that could just, according to me, cause more damage than the sleep deprivation I was suffering.

My sister arrived early to pick Dad up and under much objection he eventually went with her to see the eye specialist.

Thursday afternoon

1:55PM, Thursday, 27 Mar, 2008

Hiya

All is peaceful and quiet here. Dad is sitting listening to his radio. Short-tempered as hell, but stroke patients normally are. Alec is sleeping so I leave him. Dad never saw the eye specialist today – he and Sussa were back within the hour. They only made an appointment for him. First available appointment is for 23 April. The eye is not that serious so it can wait until then. Just have to check it out some time.

Spoke to Dr S about Alec today, expressed my concerns and he gave me the thumbs up that things are still on track with Alec. The Doctor at the MTM hospital has not yet responded to Dr S about the questions he raised, and he asked me to please contact him again on Monday.

I have made some decisions that are going to affect my life, for the better, but I will blog about it only early in next week. I can not blog about it now, as it might compromise certain decisions.

Now!!! Onto matters Jessy. Huge as an elephant at the moment. *But*, because Jessy finds it extremely difficult to blog currently (she looks like a sow at the moment), she asked me to nominate some e-god parents for her litter. She has however already indicated that Floppie and Flappie walks away with the coveted title of royal e-god bears, no two questions about that. But, e-god bears is only one set of god "parents". We are now also looking for real life e-god humans. Who do you suggest and why do you suggest them?

Take care, till later
Pieter

Notes: In hindsight perhaps it was a good thing that Dad never saw the eye specialist that day. It might just have added to his stress. What it did however do was provide father and daughter a last opportunity to do something together.

I returned Dr S's call to enquire about his discussion with Alec's specialist at Tshepong. Sadly the specialist had not come back to him yet. I must admit I was disappointed at the time but what could I do?

Jessy was becoming increasingly uncomfortable. It looked at this stage as if she was ready to give birth at any moment. She would walk a little, sit, pant, get up and walk again.

The decisions I refer to in the post was to employ Heidi Lindner as my new business manager. She was very unhappy at her then place of employment, and offered to come and assist me with Alec and Dad whilst they were recovering. I decided that I did need the help, because my business was going down the tubes fast, and Dad and Alec were a fulltime job. I could however not blog about it at that time, because it would have compromised Heidi. Her employers followed her blog and her every move, and we did not want to make the situation uncomfortable for her.

heidil here

6:25PM, Thursday, 27 Mar, 2008

Hello everyone

Once again i need to appeal to your prayers and thoughts and positive energies. Pieter's Dad has had a bad fall, and Pieter suspects he may have had another small stroke. Oupa is in bed now, and comfortable, but Pieter thinks he may need to go to hospital tomorrow!

My thoughts are with you Pieter. Remember – You will survive

Love you all very much!

Notes: Dad had a nasty fall. He got up from his chair to walk to the bathroom, lost his balance and fell onto a glass coffee table, which very nearly broke. He kept on murmuring “oh oh”, “oh oh”. It was scary to see him like that. I immediately phoned my sister and ordered her over. By the time she arrived, Martie and I had Dad in the bed already. I allowed Joey some time with Dad, and I phoned Heidi to break the news to her and she wrote this update.

Alec had an accident in bed, he lost control over his bladder and wet the bed. I had to remake the bed, and put dry linen on.

Thereafter I called Martie and Joey for a house meeting away from Dad and Alec so that we could decide what to do. All three of us agreed that Dad needed hospitalisation. The problem was, that the hospital we wanted Dad to go to, only accepts a limited amount of state patients, and you have to get a referral letter from our local clinic. And the clinic was closed by that time (it is not a 24/7 clinic). You could not phone this hospital and order an ambulance without the referral letter. So we decided to keep Dad stable till the morning and then Joey would go and get a letter from the clinic. We did not inform Dad that night that we had decided to send him to hospital. I did not want him upset or have him feeling betrayed.

RTS, Ramona and I had the following correspondence:

----- Original Message -----
From: Pieter
To: Ramona

Sent: Thursday, March 27, 2008 11:51 AM
Subject: I need advice

Dear RTS and Ramona

Some time ago a mutual friend of ours said that should I ever need her to come and run my business, I must just call her and she'll be here.

I realized this morning that a) my business is in shambles, and b) I have to make a choice – it is either my dad and Alec OR the business. And my choice is my dad and Alec.

Which has led me to thinking the time has come to ask Heidi to come and run my business. I can not offer her a salary and she is very well aware of that and does not expect it. I can however offer her 50% of the income she generates and she is more than happy to accept that. Do you think I should do it? I spoke to her and said that I am going to run it past you, and my sister.

I really appreciate your comments on this.

I will send an email later about Alec's condition and the outcome of my telecon with Dr S.

Love
Pieter

From: Ramona
Sent: 27 March 2008 12:56
To: Pieter
Subject: Re: I need advice

Hello My Friend!

I'm so sorry to hear about Dad. This has indeed been a very trying time for you, and I wish we there to offer you more support.

Pieter, this is a really tough decision to make. I so wish I had some good advice for you. There are so many things for you to consider. Right now, you're under so much pressure, and I understand that you could use all the help you can get. And Heidi is such a wonderful person to consider doing this for you. On the other hand, there will come a time (very soon) that Alec will have recovered and the two of you can FINALLY be together with no hassles, and I do recall you telling me that you'd prefer if he joins you in your business, which I think is a fabulous idea.

Perhaps once Dr S gives you more of an idea of how long Alec's recovery will take – you could take it from there.

I'm so sorry that I can't offer you better advice, I know things are very difficult for you right now.. – but please remember that we would support you in everything you do, and would like to be there every step of the way.

Please do let me know about Alec, I miss you all sooooo much! Can't wait to get back already!!

Loads of love & hugs

Ramona

----- Original Message -----
From: Pieter
To: Ramona
Sent: Thursday, March 27, 2008 1:10 PM
Subject: RE: I need advice

Hi there Ramona

There are some signs of improvement with Alec but there also other signs of deterioration. He has sort of lost control of his bladder, or let me put it this way, he sometimes forget to get up and go to the loo.

Just spoke to S who said that he has not yet had the privilege of a reply and that I should phone him again on Monday. I did however speak to Sussa and Aunty M, as I feel the Heidi question is not a decision I could take on my own. Both Sussa and Aunty M are of the opinion that I should embrace Heidi's offer. I am sure we could all come to an amicable agreement and I have asked one of my friends who's a boffin on HR matters to assist me with a draft contract, he should come and see me this afternoon some time. He must also do a Power of Attorney, or legal guardian application, for Dad. I think I am going to go with it Ramona. I have already organised a weekend jobby for her with one of my friends (the one who would have done the catering for our wedding. They always need an extra hand over weekends).

Dr S said recovery could be anything from 1-2 months, BUT as I said, he is still waiting on the data from Dr Varavia.

I miss you too. Sussa seems to understand finally what I am going through and offered her assistance as far as possible. Promised to pop in regularly, and said I should call any time I need her.

Thanks for the points you mentioned below. I really appreciate. About 10 more days and you are home.

You take care.

Love
Pieter

From: Ramona
Sent: 27 March 2008 13:27
To: Pieter
Subject: Re: I need advice

Hi Pieter,

Thanks for the update, too bad that Dr S hasn't had a reply. It sometimes feels like a long waiting game!

Brilliant idea to draft a contract and also wise to do a Power Of Attorney – you have everything covered, and I think it's wonderful that you'll have someone to be there for you full time. I admire you for doing it on your own for so long! BUT it can only get better from here, right??

RTS is still at site, and will only be back tomorrow. The girls and I toured the city for a while today, until we got horribly lost, and had to catch a taxi that didn't look safe at all! My heart was racing!! But we got back to the hotel safely, and spent the rest of the day at the pool. That will teach me to stick with the driver in future!! LOL

We're off to dinner, I think we'll have Sushi for a change. Will chat later.

PS HOW is Jessy doing??? She must be huge!

Love to everyone!
Ramona

From: Pieter
Sent: 27 March 2008 13:35
To: Ramona
Subject: RE: I need advice

Thanks you made me laugh….

When I was in Bangkok, I was warned prior to travelling, don’t try and walk anywhere, as everything looks closer on the map than what it really is. And I had a look at the map and said to myself the person who said this to me must have been out of her skull. So I set off. Two hours later I wasn’t even a quarter way to my destination which I thought was only a brisk 30 minute walk away. Needless to say, I took a cab who decided to give me some sightseeing as well for something like 20 BAHT (BARGAIN BARGAIN BARGAIN).

Hope you enjoyed the Sushi.

Jessy? HUGE and does not leave my side for ONE minute. I wish the babies are born – Dad needs some cheering up.

Love from here as well – Alec sleeping a bit.

Take care friend
P

And later:

From: Pieter
Sent: 27 March 2008 14:03
To: Ramona
Subject: Good sign?
Hi there

As I am typing this I am looking at Alec in the mirror – and his face is turned towards the mirror. He is sleeping. But ALSO smiling!!! In his sleep! Can you believe? Awesome!! I sure read that as a very good sign!

Take care
P

Decisions Decisions Decisions

3:50AM, Friday, 28 Mar, 2008

Morning all. Or shall I still say good evening

I have been up since 3am. It feels as if my whole world is falling apart. I have to get adult diapers today. Not only for Alec, but also for my dad. I feel powerless, helpless and as if too much has been given on my plate at one time. At the same time I sit with my dear Jessy, who I believe is going to give birth any moment now. I can see, because she is starting to do what I call nesting.

Thankfully Sussa is here as well, though to her system this is still a major shock. I am used to it to some degree already; Sussa is only now confronted with the stark reality of it all.

Decisions need to be made today, and which way to go, ai, that is the question. I know Dad needs to be hospitalised if I am to prevent a second stroke. He is extremely disorientated and his speech has become affected even further. Alec has lost control of his bladder and is now reduced to nothing else than a 85kg baby.

How long before I lose my head, too?

I have to stay strong, and I know it. But *how*? If I have nothing on earth to work with. How???

Anycase. Before I transform into a whinging, attention-seeking moffie, let me rather stop and see what I can find that can assist me.

Cracking up me,

Pieter

Notes: Sleep just would not come on that night. So I got up. My whole world was falling apart. I was in despair. Alec had another accident in bed. Dry bedclothes were needed again. And it felt as if I was dealing with a dead weight as I moved him and changed his clothes

Ramona and I exchanged the following emails early in the morning:

From: Ramona
Sent: 28 March 2008 05:20
To: Pieter
Subject: Re: good sign?

Hi Pieter

I just read your blog. I don't want to sound like a broken record about keeping strong etc. I want to say that I think you've made an excellent decision with regards to Heidi. You need all the physical help you can get, and God has sent her to you. Words of encouragement aren't good enough now. I don't want you to crack up now, you've come too far for that, Pieter. Do you have any idea when she will be there? Would you like us to see if we can get a nurse or someone to help you temporarily until she gets there?

I so wish I could be there for you right now. I know it's not easy, but take things one step at a time. Sort Dad out first, I think getting him to a hospital with proper care is a brilliant idea. Once he's seen to, you'll feel more at ease.

Please let me know if there's anything I can do from my side, I'm truly concerned about you Pieter!

Love to you all. Hang in there.
T

From: Pieter
Sent: 28 March 2008 07:22
To: Ramona
Subject: RE: good sign?
Importance: High

Dear Ramona

Apologies for the belated reply. I just did not want to say yes or no without consulting the other two people concerned – Aunty Martie and Joey, my sister. Although I am now the head of my family, I wish to do so on a consulting basis and not on an authoritarian or autocratic basis.

I would like for you to see if we can get a nurse to temporarily help out until Heidi is here. I will know on Monday 31/3 when she will be able to start but my guess is towards the end of next week, as she still has matters to take care of in East London.

I have also been thinking since 3 this morning whether I should or should not hospitalise Dad, and my decision is to do it. I am just waiting for 07:30 to arrive so that I can phone my contact in the clinic to organise for me that Dad rather goes to Duff Scott hospital and not Tshepong. Also to organise adult diapers for Alec. He has lost control of his bladder completely

I am going to be brutally honest with you – I am preparing myself for the worst for the both of them – should a miracle happen, I'd be eternally grateful, if not, at least I was prepared for it then.

Sorry to spoil your holiday like this, and thank you for allowing me to push on your button once again.

Love and care
Pieter

heidil here again!

1:52PM, Friday, 28 Mar, 2008

Oupa, Pieter's Dad, has been admitted to hospital. He is not looking too good, and of course he is not too happy to be there, but for the moment, it is the best place for him to be, where he can be monitored to prevent him from having further strokes. At this stage we do not know how long he will be there, but it will definitely be over the weekend.

Plans are afoot to get temporary help for Pieter, as he has realised that he can't cope with this on his own, and a long term plan which will assist Pieter is in motion. As soon as we have specifics one of us will let you know!

And then, just as if things are not stirred up enough, Pieter suspects that young Jessie is in labour. For me this is a good sign – new life!!! We are all waiting with bated breath, Pieter as to how many puppies and if anyone guessed the date and the amount of puppies right!

Thank you once again for all your well wishes, your ideas, your emails, smses, comments and offers of help. Each one is much appreciated, and while Pieter is unable to answer everyone personally, please know that all have been received with love and speak of the empathy that everyone has with this very difficult situation that has befallen our quiet friend.

Please keep those prayers, positive thoughts and wishes coming. This is a time where Pieter needs to know that he is not alone and has the support of all his blog friends.

Lots of love from everyone in Jessie's Queendom, and of course from me, by the sea!

Lord, please surround the house in Quiet Fountain, and the hospital where Oupa is with your angels. Please let each one of the members of this family feel their presence and help to keep them calm, positive and focussed. You have carried them thus far already, and for that I thank You. Please give Pieter the extra strength he needs for the next few trying days, and please allow the hearts of those upon whom the decisions for the long term plan rest to be opened and filled with understanding so that this plan can be set into motion as soon as possible.

In the name of the Father, the Son and the Holy Spirit
Thy will be done
Amen

Notes: That morning, I asked Joey as she is also an early riser, to do two things for me: to get the note from the clinic, and to purchase some adult diapers for Alec from the pharmacy. Joey set off on her task while Martie was to get Dad ready but without telling him that he was going to hospital.

Joey came back with the diapers and the letters and said that an ambulance was on its way. We took Dad to the lounge where I tried to explain to him why we felt that he needed to go to hospital. He just shook his head vehemently and objected. The last thing I wanted. When the ambulance arrived, I led the ambulance men into the lounge with the stretcher. Dad got up as if to go to his room.

It was a rather challenging situation, because I did not know how we were going to convince him to go to hospital. Joey pleaded, but he dismissed her (we could not understand what he was saying). Martie tried, but he just marched on towards the bedroom. I tried, but he just waved me away. The ambulance men said we should calm him down and bring him in the car later. I was nearly ready to see them off when we noticed that Dad had just wanted to go to the bathroom. After he finished, he came out of his own accord to where the stretcher was, got on and off he went to hospital with Martie with him in the ambulance and Joey following in her car.

I went to put a diaper on Alec, explaining to him that it was only a temporary measure. I could see the hurt in his eyes, but I had to. He had already lost all control over his bladder, when would he lose control over his bowels too? My first attempt at putting a diaper on an adult was not a success, and my thoughts about him losing control over his bowel movements were not even cold when it happened – all over the bed.

I took Alec for a shower, discarded the wasted diaper, took the mattress outside to be cleaned, laid Alec down in the guest room, picked up the phone to Peter and asked if he would not mind to come and baby-sit Alec whilst I was tending to my own ablutions.

Peter and his wife, Magda arrived to come and help me. Peter later left because he had other commitments, but Magda stayed so I could quickly run some errands (which I relied upon my Dad to do for me thus far). I returned to find Alec was sleeping peacefully. Later that afternoon Magda helped me to make a plastic cover sheet for the mattress, in case we had an accident again like we had that morning.

A little bit later he woke up and took his duvet and went outside to sit under a tree for a while. Joey and Martie returned from the hospital around 12:00. Joey phoned Martie's son, who lived in Rustenburg, and asked him to come through and try and give his mother some moral support. He and his wife came through but only spent half an hour with Martie before going off in another direction.

To this day, I feel as if I betrayed Dad by admitting him to hospital.

My last post – for a while

9:17PM, Friday, 28 Mar, 2008

Hi there, dear friends

I am sitting here – bawling my eyes out. I am tired, I am worn out, my nerves are in shreds. I just came back from the hospital's evening visit, and Dad is not looking good. It's not an easy task to look at Dad with a straight face and say everything is okay at the house, he does not have to worry about a thing, And say it with a smile. It is not an easy task to say to him Alec is getting better, whilst I know Alec is not getting better.

It is not an easy task to come home and see Alec, not recognising anybody at all. It's not easy to change a diaper on an uncooperative adult male.

It is not easy to run a household, run a business and have this on your plate. I wish I knew *what* it was that I have done wrong to deserve this.

Alas, I received an email from MissTiGGeRr's sister today *(thanks so much)* and I realise I am not an island. My name starts with a P and ends with an R and I am human. My name does *not* start with a G and ends with a D. And thanks to MissTiGGeRr's sister, I AM going to allow myself to be human. Not easy though, with such a lot of people expecting miracles from me, but I'll try.

I am taking a break from blogging for a while. I told Heidi, and she said she would do updates. I might pop in and leave an odd comment, or even do a post, but at the moment I want to focus *all* my energies onto the two men in my life. I do not know how long I will have them still, so I want to make the most of it. I will read blogs from time to time, when I sit and watch Alec drift off to that far off place in his mind in never never land. But that is about it.

Just thought I'd explain my sudden departure – I originally left it for Heidi to do, but thought better of it.

Jessy is in labour – poor thing. Methinks if she could kill Milo right now, she would. I feel so sorry for her. As yet no baby has made its appearance, but I will let Heidi know the final number – all of them should be there tomorrow morning.

You take care blog friends. And thanks for carrying us through this time.

Love
Pieter

Addendum to post:
God BLESS Hutton. She phoned shortly after I made the original post. And at precisely the right moment, and I could cry. And then she gave me advice. Very sound advice! Thanks Hutton. I appreciate.

Notes: I was very down and out. I was tearful, not caring anymore if Alec saw me cry or not. Alec was extremely restless.

I went to see Dad that evening along with Martie's son, his wife and her mother, Ina, Martie's sister in law. Joey and Martie remained at home to look after Alec. Dad was not looking well, very unsettled and I was still overwhelmed by the feeling of betrayal. I went through Dad's hospital file and saw that some tests had already been carried out. What DID impress me though was the condition of the hospital – I was expecting something like Tshepong, but there was none of that. The hospital was clean and tidy and I saw that Dad actually had an Afrikaans doctor.

I was watching some television in the room with Alec, contemplating ending it all later that night. It would have been easy for me. I would just lock the door, sit down and light a Fumitab. It could not have been easier. But something kept me going. Maybe Alec was at his worst, and from there on it could only get better.

I also wondered how I was going to going to look after Dad and Alec. Joey pointed out to me that she would not be able to come and help me every day. Her work was very important to her – she could not help to the extent that she would like to, as it would put her job at risk.

A fellow blogger, I can't really remember who, had given my cell number to a blogger named Hutton. Martie and Joey had gone to sleep already, and it was some time after 21:30 that I received a phone call from Hutton. What was nice about this phone call was that for the first time since everything happened, I could open up and cry to my heart's content. Hutton, a lovely lady working with the elderly, gave me some very sound advice which perked me up Big Time and picked me up from the gutter.

Because Alec was so restless, rolling from side to side on the bed, I decided that I needed sleep desperately. I opted to sleep in my high back office chair, but that was very uncomfortable, so I took the blanket and slept on the floor on Alec's side of the bed. Some time during the night at around midnight, Alec woke up and saw that I was sleeping on the floor. He tried to pull me up onto the bed, and when I got in next to him, he put his arm over my chest and fell asleep restfully. To me that was special. It was another little grass blade to cling to. He was aware of what was going on around him. And it gave me hope.

heidil here – Saturday morning update

10:19AM, Saturday, 29 Mar, 2008

Hi everyone

Sorry i'm only posting now, I've been busy with admin and all the other things that need to happen in a B&B.

As Pieter explained on his previous post, I will try and keep you all updated as much as possible. This may mean there will only be one update per evening, but I will see if I can slip other updates in as well during the course of each day! I may also alternate between my blog and Pieter's blog.

Oupa is unchanged. When Pieter phoned the hospital this morning they gave him their standard answer, but as you know if he had taken a turn for the worse, they would have contacted him. Aunty M and Sussa will be visiting Oupa later and we'll know more how he is then.

Alec had a very restless night, to the point where Pieter ended up sleeping on the floor beside his bed. During the night Alec did wake up and tried to get Pieter to get back onto the bed with him. This is a good sign, it shows that he is aware of what is happening around him.

Young Jess has still not had her puppies! As of this morning she was running around happily, but Pieter said she did sort of stop and push every now and again, so these much awaited little bundles of fur are imminent and I think, as in human first deliveries, they will take their own sweet time to make their appearances.

As for Pieter, Hutton, your chat last night really perked him up! Thank you for that and for your advice. He is going to act on it today! This morning I could tell that he is really feeling very low, and I tried to perk him up with a few jokey comments (one good thing about Pieter: he understands my rather strange sense of humour!). So what I would like for each of you leaving a comment for him to do is to also try and boost his spirits a bit. Maybe you have a funny little poem, or a saying, a limerick that you can post for him – to help bring a smile to his face. As he has said he will be reading comments during the times when Alec is sleeping, and those are the darkest times for him. As he won't have much time to read individual blogs and posts, I ask that you leave the comments on his blog, and maybe if you see your way clear, to leave a link on your own post, so that we can collect a number of smiles for Pieter in this way.

So I, in my official capacity as Pieter's Scribe, declare
Operation Leave a Smile for Pieter
officially open.

Love to you all
Heidi

Notes: There is not much I can remember about this day really. I know Martie's son and his wife came to say goodbye. I know Joey spent the day with us.

And I remember Alec defecating on my hand. He remembered he needed to get to the bathroom, I helped him get there, but I could not get the diaper off quickly enough and he could not hold it in anymore. It sounds gross, I know, but I really did not mind doing these little things for him. If it would have made him better, I would still have been doing them to help him.

I know other people drifted in and out of hospital and in and out of the house. But I cannot remember most of what happened that day. I know Annemarie was there and Simmi, I remember Annemarie crying when she saw Alec, but on my request she went outside to cry. I remember her asking “Why, why, why?” Alec did, however recognise her (another little positive sign).

Sunday morning – heidil

9:13AM, Sunday, 30 Mar, 2008

Morning everyone

I've just spoken briefly with Pieter. He had a good night’s rest, as he took a sleeping tablet, and Alec was also not as restless last night, so he sounded quite chipper.

He was at the hospital with his dad, waiting for the doctor to do his rounds, as there are a number of questions he needs to ask. His dad's condition is unchanged.

Jessy has still not given birth! We assume that the contractions she is experiencing may be similar to the Braxton Hicks contractions that humans get! She is fine otherwise and in between contractions is running around and eating and doing all her usual doggie things! But one thing is certain, those puppies are due any day now.

Thank you for all the smiles you posted. Please keep them coming!!! And please keep everyone in the Quiet Fountain home and hospital in your thoughts and prayers. Pieter and Sussa and Aunty M do need your thought support now more than ever, and knowing that they are not alone in this, makes all the difference to them. Thank you one and all!!! Each one is appreciated!

And as Pieter likes to say, don’t forget to tell your loved ones you love them today!

I may not be able to post another update today, but rest assured, there will be one tomorrow!

Notes: I needed to see Dad's doctor. So I phoned the hospital and they suggested I be there at 10:00 when the doctor went on his rounds. So I waited from 09:50 to see him. Joey stayed behind with Alec. At 10:30 the doctor had not been around, so I left my telephone number with the staff and asked them to phone me when he arrived.

I arrived back home and immediately saw Alec was really not well. He was severely dehydrated. I realised I needed to get him to hospital, but did not want to take him back to Tshepong, but rather to Duff Scott. He could hardly stand upright.

In between I had to assist Joey with food preparations as she and her children were coming through for lunch (she left shortly after I arrived to go and fetch her children who were staying in Potchefstroom).

I phoned the sister in charge of our clinic to explain the situation and to see if there was anything she could do to give me a note to take Alec to hospital on a Sunday. She explained she could not, but she did come around to the house to see if Alec was okay. She said he was fine still and that I should wait until the morning and then come and collect the note from her. She suggested I give Alec some Rehydrat.

Somewhere in between I remember Alec trying to get up from bed, but he was too weak, and immediately fell onto the floor. After helping him back onto the bed, he just turned on his left side and stared out of the window – he wanted to be outside, and couldn't. I felt so much for him that afternoon. It would be the last Sunday he would spend in our house. It would be the last time he would look out of our bedroom window. And I did not know it.

In the meantime, Ramona and I had the following conversation:

From: Ramona
Sent: 29 March 2008 17:29
To: Pieter
Subject: Thinking of you!

Dear Pieter,

I haven't heard from you today, I'm sure you have your hands full over there! How's everything going? And Jessy? I hope she's doing okay!

Have you had any success in finding someone to help you? I've spoken to a friend of mine who will try his best to see if he can find someone in the NW, but I'm hoping you find someone that you're comfortable with. When you do, please send me the payment details & I'll take care of it.

I'm sorry this is just a short note again, but things are a bit hectic as well as a tad tense here with regards to the project ... will tell you more in detail once I'm back.
Love to everyone there,
Ramona

From: Pieter

Sent: 30 March 2008 17:41
To: Ramona
Subject: RE: Thinking of you!

Dear Ramona and RTS

Sorry to say that I am re-admitting Alec to hospital as his condition is deteriorating swiftly now.

We are lucky to get him into the same hospital as my dad, but we can only admit him on Monday. Duff Scott is one of the better hospitals in the area.

Despite my bests efforts he is severely dehydrated and he needs to get onto drips as soon as possible.

We did find someone to help me with Alec, but we will wait with that pending his discharge from hospital. If.

I will keep you posted on his condition.

Love
Pieter

I know I said ...

8:59PM, Sunday, 30 Mar, 2008

… that I am taking a break from blogging. But my heart is sore, I am crying out of sheer frustration and I just feel ... lonely?

Alec is being re-admitted to hospital tomorrow. I just cannot give him the care that he needs. As pure and simple as that. And the way he is at the moment, I'd be lucky if he is still there when I wake up.

He is *not* going back to his first hospital. He is going to the same hospital my Dad is at. We have found a way that he can be admitted there, and it is *much* closer to home, and it is a better, cleaner hospital. The reason Alec went to the first one is that they have all the facilities. So if they need C/T scans, they will have to transport him to the first hospital to have it done. *But* their *care* is better though.

Dad's not well; he did not recognise me this morning. And when Sussa and Aunty M went to visit this afternoon he was full of beans – wanted to take his drip off, wanted to get out of bed, and became downright angry because they would not take his drip out. We were asked *not* to visit him tonight as our visits seem to unsettle him.

I did speak to his doctor this morning and he was non-committal as to prognosis. He did however say that I must remember that Dad is old and had a full life. So I am left to make my own deductions. I also spoke to him about Alec and having his file at MTM1. Would MTM2 accept a patient from MTM1 and he said because Dad is there, and because Alec is from the same family, they would transfer his file from MTM1. *However*, red tape prevailed and I needed a letter from the clinic, and the clinic is closed. Phoned the sister in charge at home, discussed the shituation (sic) with her, and she said that because they are not a 24/7 clinic she could not give me such a note. Last time she did, it nearly cost her her job. She did however make the effort to drive out to us, to assess Alec, and to assure me that he would be fine until morning. And she will arrange for the transfer of the files and everything.

I am tired – dog tired in fact – and doubt I will sleep tonight. So be it. If only I can get Alec on a drip tomorrow, I'd be the happiest man alive.

I also read, with interest, Riatsila's latest post about attention seekers, and am happy to announce that I do not conform or even remotely have any of the characteristics our local psychologist dishes out. It is however a well-researched post, and those characters he portrayed do exist in real life. You just have to travel to India (for instance) to see to what extent some parents would go to grab attention – lopping off their children's hands just so that they *have* to beg in order to get income. Sad but true.

What I am sharing however, is true life, realistic, day to day, realism. More realistic than Idols or Big Brother 2, because there they are afforded the luxury of cutting out the unsavoury bits.

Guys, girls, I hope I can give you good news via Heidi tomorrow. For me, I am preparing for worst case scenario. Forgive me for that. *But* only if you've lived it yourself, you'll know what I am speaking about. Anything better than that is a blessing and a miracle.

The pink pill is starting to kick in now, so I should be off to bed

Pray for Alec and my dad, please. I'm unimportant, just an instrument in God's hand, they need the prayers – not me.

Love

Pieter

Alec – my man – I am not sure you will ever be able to read this. But I do love you. And nothing will ever change that! EVER!

Notes: MTM = Manto Tshabalala Msimang. MTM1 = Tshepong Hospital.

MTM2 = Duff Scott Hospital.

This was another blog post reflecting my despondency. I felt lost, I felt as if Alec and Dad were busy dying. I felt out of it. Jessy did not want to give birth. We could not visit Dad that night because he got upset when Joey and Martie were there in the afternoon and had wanted to come home with them, so the staff asked us not to visit him that night. Riatsila did another post that was aimed at me, in which he claimed that I was seeking attention. Alec had taken in very little fluids. So I was down at my wits end – I did not know which way to go anymore.

Joey returned to her home after the afternoon hospital visit, so it was just Alec, Martie and I at home. The first night where it would be the three of us – and the last night where it would be only the three of us.

It would be the last night that Alec and I shared a bed.

I did not know. I never imagined. Despite knowing he was gravely ill …

Monday morning – heidil

9:02AM, Monday, 31 Mar, 2008

Morning everyone!

I haven't as yet spoken to Pieter today, but I see he updated you all last night.

I am going to be doing this brief update, and possibly will only be able to do one again tomorrow from an Internet Café, as I have resigned, and will be moving up to Quiet Fountain as soon as I can to help Pieter wherever I am needed.

I am to leave the B&B by this afternoon, so as you can imagine there is a lot of admin that I need to do before I hand everything over.

If I can slip in an update later, I will.

Notes: This is the first post indicating that Heidi decided to move to Stilfontein to come and help me.

We had had a long chat when Heidi came to visit on the 5th of March, and Heidi indicated at that stage already, that should I need her to come and run my business, I must not hesitate to contact her. I discussed this with Dad and he was open-mouthed with amazement – a complete stranger wanting to help other complete strangers out in their time of need. It was this gesture that gave Dad 90% of his trust in Heidi. The other 10% came from meeting her on the 5th.

Quick update – Monday late morning – heidil

11:57AM, Monday, 31 Mar, 2008

Hi, I've quickly slipped away from my admin to give you this update!

Pieter hadn't phoned me earlier because he had accompanied Alec to the hospital and up until now has been sorting things out there.

Alec is now settled in at the hospital – he was given a valium injection which has calmed him down immensely and when Pieter left him a short while ago he was sleeping peacefully. As you know Pieter arranged for Alec to go to the MTM 2 hospital, and both Alec and Oupa are in the same ward, a few beds away from each other. Alec's new doctor is very thorough, and he will be working in close conjunction with the specialist who saw Alec last week.

Pieter has also found an occupational therapist/psychologist who will be helping him through this, and also Alec, when he improves.

Oupa's condition is much the same as yesterday – Pieter went to see him, but he was sleeping, so he didn't want to disturb him.

Pieter is much relieved, and extremely tired, and will have a good night's rest tonight.

Your thoughts and prayers have gotten these wonderful, salt of the earth people through so much already. Please keep them in your thoughts over this very difficult time, and once again thank you to all of you who are sending encouraging mails, smses, phone calls to me and to Pieter – we appreciate them all!

Oh, and Jess still hasn't given birth – methinks those are going to be April Fool puppies after all!!!

Lots of love from both of us, and by default the rest of the Quiet Fountain family!

Notes: I was at the clinic early that morning to see Sister Irma. She phoned Tshepong hospital to get info on Alec as well as get his latest CD4 count. It was a whopping 383 – pointing well against PML because PML thrives on low CD4 counts. She explained to me that it very often happens in HIV cases that someone will turn around on the verge of death – it lifted my spirits.

Prior to going to the Clinic I phoned Peter to ask if he would mind sitting with Alec whilst I was away. Alec was a heavy lad and Martie would not have been able to help him if he had tried to get up and fallen.

I arrived back home from the clinic, sat down with Alec and started writing out an observation list for the doctor at Duff Scott. When the Ambulance arrived, we transferred Alec from our bed, with me accompanying him, were driven all the way through Stilfontein to Duff Scott. Alec kept on tossing and turning on the trolley.

On our arrival at the hospital we proceeded to Casualty for Alec's pre-admission check ups. There I met the man with whom I would work with throughout Alec's hospitalisation – Dr Dave Griffith (deceased). Not the most talkative person, but evidently very thorough and very empathetic. I gave him the observations I had jotted down, and he thanked me for them.

After Alec's pre-admission check-ups, he immediately administered Valium and thereafter a drip. I asked the doctor to which ward Alec would be assigned and he replied it would be in the same ward as my dad. I requested that Alec be placed in such a way that the two of them could not see each other. My reasoning for this was that I did not want either of them to get shocked by the other one's deterioration. The doctor agreed that it made sense and that Alec would be placed in a different section in the same ward. As it turned out, Alec was placed in an isolation ward.

Peter came through to the hospital to collect me and bring me back home. Martie and I drove through to visit at both the 15:00 and 19:00 visiting hours. Dad was not looking well and did not take well to the news that Alec had been re-admitted to hospital. I kept on re-assuring him that Alec was only there for some drips and then he would be discharged again, which kind of settled him a bit.

Ramona and I had the following email correspondence this day:

From: Pieter
Sent: 31 March 2008 12:34
To: Ramona
Subject: Alec

Hi there guys

Alec is safely back in hospital, on Valium to calm his restlessness down and on a Ringers drip at the moment. His latest CD4 count was 383 which has me ecstatic.

I am seeing an Occupational Therapist / Psychologist on Thursday at 11:00 to help me deal with the trauma surrounding Alec and my dad.

Heidi indicated that she will be here around Saturday.

Hope your time has improved and that all is going well there.

Love
Pieter

Later that night Jessy appeared to be in labour.

Tuesday afternoon – heidil

12:32PM, Tuesday, 01 Apr, 2008

Pieter received an email this morning from the 2nd specialist confirming that likelihood that Alec has PML. This is what we had been praying and hoping he didn't have, as this is the incurable and untreatable viral infection.
As you can imagine Pieter is devastated with this news.

As I am office-less at the moment, I won't be able to do as many updates, but will try to get to an internet café to do as many as I can. Pieter will also not be blogging for some time, as he wants to spend as much time with Alec and his Dad as possible.

I am trying hard not to cry as I am typing this post.

Jess has had some complications with the birth of her puppies. Her first puppy was stillborn early this morning, and Pieter is on the way to take her to the Vet.

Please, everyone, keep Pieter and Alec in your prayers and your thoughts. They need to know that they are not alone in this.

Notes: I was shattered by the news in the email. I had informed Dr S on the 31st of March that Alec had been re-admitted to hospital and that he was now under the care of Dr Griffith. Dr S emailed me to tell me there was a strong likelihood that Alec had PML. Something inside me said it could not be true, so I e-mailed him back and asked if I should try and obtain the MRI plates for him so that he could view them and make doubly sure. On 1 April he sent me this e-mail:

From: D S
Sent: 01 April 2008 08:23
To: Pieter
Cc: Ramona
Subject: RE: Alec de Lange

Pieter

Thanks for the note. I doubt that it will be necessary for me to see the plates. From what Dr Variava has said it seems very likely that PML is a player (together with the HIV) and the decision would be whether to attempt any treatment for this condition? All of the drugs that have been tried (cidofovir, interferon alpha, cytarabine, etc.) have had fairly limited or no success. The greatest value has been in reconstituting the immune system with antiretrovirals.

I would suggest that Alec continues with the ARV's and that his immediate physical needs be addressed in the hospital i.e. that Alec receives good and compassionate medical and nursing care.

Pieter, I am very happy that you are going to see someone who can counsel you as this is a particularly difficult time for you and you will need to try to do the right thing for many people including the two you love, your partner and your father, and yourself. I suggest keeping your local doctor, Dr Griffith, in the loop as much as possible. It will help to have him on your side. Irrespective of whatever treatments may need to be looked at, the bottom line is that Alec will need reliable and compassionate care on a daily basis.

You want to ensure that the channel of care remains optimal throughout. I am happy to discuss the merits of anti-PML medication with you and with your local doctors. At the end of the day it would be one of my colleagues in your region who would have to make the decision on whether to attempt any of the experimental treatments that are being used elsewhere. My guess is that these treatments might prove to be rather expensive but those issues can be discussed at the appropriate time.

With regard to your taking further training in the HIV field, Pieter, you shouldn't consider anything like it until your present situation has normalised and you have had a good year or so to settle back into a normal existence. So don't go down this road at this time. But it may be worth pursuing at a later stage.

D

At home, Jessy gave birth to a still-born puppy and she was having difficulties in delivering the rest of the puppies. I had to rush her to a veterinarian in Klerksdorp for a Caesarean section. She would do the Caesarean and see how many puppies she could save, and then bring Jessy back with her to her consulting rooms in Stilfontein in the afternoon, from where I could fetch her. At about 14:00 she phoned me to say that there had been only one more puppy, that it was also dead, and that it was abnormally large – Jessy would not have been able to give birth to it naturally.

I never told Dad or Alec that Jessy had two stillborn puppies, as I did not want to upset them.

Jessy – by Pieter

6:34PM, Tuesday, 01 Apr, 2008

Hi there

With sadness I have to inform that none of Jessy's litter survived. Jess started giving birth this morning and the first baby was stillborn. Cute little bitch. We thought the other would follow, but eventually I had to take her in to the vet for a caesarian section. There was only one more baby – about 4 times the size of the first one, and she would not have been able to give birth to it naturally in any case.

Jess is safely back at home and lying in her basket, feeling very sorry for herself and with good reason. I'll give her some extra pampering.

Off to hospital now.

Care
Pieter

Notes: My whole existence came down shattering around me. I remember feeling so down, so despondent, so finished. That afternoon we went through to the hospital to visit with Dad and Alec. This would become routine for the next few days – spending some time with Dad and then spending some time with Alec. Alec was very restless and the Valium did not seem to calm him down. And when he was awake he had this haunted look in his eyes, eyes that followed you around.

Later that night – I was extremely exhausted and just wanted to sleep, and decided to miss out on the evening visiting hours and rather just phone and get an update – I was given a fright. I had phoned the hospital and asked to be put through to Alec's ward. When I asked the nursing staff how Alec was, and they told me he was worse. So I asked if it was necessary to come through and the gentleman replied that he thought it would be wise. I jumped in the car and raced through. Upon arrival I saw it wasn't the same night staff who had been there the previous night and raced through to Alec's ward. Only to find that Alec actually looked better than the previous night. The night staff had nothing to compare Alec against as he was earlier, because it was the first time they had seen him. I was angry initially but also understood what had happened.

Some email correspondence I had with Ramona and RTS that day:

----- Original Message -----
From: Pieter
To: Ramona
Sent: Tuesday, April 01, 2008 12:23 AM
Subject: FW: Re Alec

Hi RTS & Ramona

For your info – am I following the right route here?

Many thanks
P

PS: NOW I am going to get a bit of shut-eye – I am exhausted! Oh yes – important – Dr. S told me telephonically that there is chemical treatment currently available for PML, but it is in the developmental phase and NOT YET available in SA and VERY expensive and CANNOT be guaranteed. Meds will have to be sourced and imported via a local medicine house. I have, as you have seen, requested more info on this.

From: Pieter
Sent: 31 March 2008 18:20
To: Rainy
Subject: Re Alec

Hi Rainy

Again thanks for your offer for help. I recall a message you left on the blog where you said that should there be a problem with Alec's file and information being made available to Dr S, I should contact you.

Rainy, I had a call from Dr S that says that Dr Variava (Alec's original doctor) is quite adamant that it is PML that Alec has, and that he (Dr

S) can not concur with this information if he has not seen the plates himself. I am not sure that Dr S asked to see the plates, and I do not wish to incur extra costs for my benefactors either before we have exhausted potential existing avenues. Is there any way that your offer still stands that we can get Alec's MRI and C/T plates to Dr S without breaking rules and upsetting people?

You might have read that Alec is back in Hospital now – I succeeded in getting him admitted into the same hospital my dad (who suffered a stroke) is in. They are in fact, lying in the same ward. I have now, however, reached a stage where I will leave no stone unturned in helping Alec.

If you can help, please let me know what you need from me.

Many thanks
Pieter

From: Ramona

Sent: 01 April 2008 17:25
To: Pieter
Subject: Re: Re Alec

Dearest Pieter,

Words cannot express how heartbroken we are to read about both Alec & Dad. We're so sorry that we can't be there for you right now. We tried to get an earlier flight back, but this is proving to be impossible ... Either way, we'll be back on Saturday, and although there's nothing we can do to change the situation, at least we'll be there to offer our support.

Dr S seems extremely caring, and hopefully with his help we will be able to get through this.

We're very pleased the Alec & Dad are in good hands, they will both remain in our thoughts and prayers.

Did you speak with Rainy? I think she has some pretty good ideas & suggestions.

Sorry about the short, choppy email, but internet is very limited here, and everything costs an arm and a leg.

Please send all our love and hugs to everyone, we'll see you all soon.

Loads of love & hugs,
RTS & Ramona

PS How's Jess?

I am running on empty

10:22AM, Wednesday, 02 Apr, 2008

I am writing this post not so much as an update as to what is happening. I am writing this post so that I can start to order my mind, accept the inevitable and have something to work with when I see my therapist tomorrow. I write this as a desperate plea from my body for some sanity, some answers, and some guidance.

These are the two men in question. Not so long ago, in fact. September 2007. Zambia. About two hours before our first bungee jump together. Having coffee in the early morning – Dad has not even yet combed his hair.

Dad lived for his little trips into Africa. Those short little holidays we could have together as a family. It was Alec's first trip out of the country.

This photo was taken just after our helicopter ride on the same day – a first for both of us. We were so close that day. We have done a bungee jump earlier, inspected some hotels at the falls, and the helicopter ride was a break between the first three hotels and the next three hotels, before our sunset cruise on the Zambezi.

We had such big plans. We were, at that stage, planning an educational for Travel Agents to Vic Falls. I was beginning to mentor Alec to take up a role in my business. We were going to get married on the 15th of March. Now my mind is searching the perfect location to scatter his ashes when one day he pass on.

Now all of our dreams lie in shatters. And my question is *"why?"*. I keep on asking myself this question, over and over and over. The next question is *"What have I done wrong* (to deserve this)?" My next statement is *"I believe in a God of love – why does he allow this to happen to me?"*

I don't know any more – I am running on empty. Empty empty empty. And the only light at the end of the tunnel I see is a train approaching at the speed of light.

Notes: I was extremely despondent this day. The gravity and the severity of the situation sank in. I was overwhelmed by a sense of grief. I was lethargic and did not feel like doing anything. Not even cooking. Then I received a phone call (can't remember the name of the person who called – but he was from Pick 'n Pay). He said that a lady by the name of Heidi Lindner from East London had phoned him and explained my situation to him and asked that they, Pick ‘n Pay, come and deliver ready prepared meals to a certain value to our house. She had already paid the money into their account, but he did not know what to deliver, and could I perhaps help him make some choices. I was so overwhelmed that I nearly started crying. Heidi just knew that I would not have the energy to even worry about food. So she took in upon herself to organise for the food to be delivered to our house. Someone dropped the food off at about 17:00.

Annemarie came to visit that afternoon and we had a discussion about Alec, whether he should go to a hospice or not when he got better. It was just a preliminary discussion.
We do not have suitable hospice facilities for HIV patients in Stilfontein. Also, I was opposed to Hospice but I also had to think of Alec’s dignity.

Some correspondence I had with RTS and Ramona that day. It was in response to their email they sent me the previous day:

From: Pieter
Sent: 02 April 2008 07:43
To: Ramona
Subject: RE: Re Alec

Morning my angel friends

Please do not apologise. I really understand and I so do appreciate all you have done so far.

I expect a call from Rainy today some time and look forward to what she has to say. Shame, she is so sweet, she even offered to come here for the weekend and help me, even if it is to wash my dishes she said.

I have to be honest that I am not holding up well. In front of Dad and Alec yes, but at home I am very tearful, desperate and despondent. I am starting counselling tomorrow though and am actually looking forward to it. It will do me the world of good to dump on someone else.

This morning they said that Dad is looking better but that Alec is still very restless “but OK”. I have sought an appointment with his attending doctor, Dr Griffiths, so that we can discuss the road ahead with Alec.

Jess is better after her little op yesterday, she lost all (only 2) of her babies. One was stillborn and the other had to be removed by caesarean section. He was too big to have been delivered normally (a little giant, the vet said).

I’m afraid my dear friends, this is all the news I have at the moment. You take care and enjoy your last few days over the seas.

Love
Pieter

Decisions Decisions Decisions – Part 2

7:43AM, Thursday, 03 Apr, 2008

Good morning

That old Beatles song reverberate through my head: *Yesterday, all my troubles seemed so far away …*

Today is kind of a D-Day. Here's the rundown.....

I am seeing my Therapist for the first time at 11:00.
I am seeing Alec's doctor at 12:00
I am seeing Dad's doctor shortly after Alec's doctor.

Feedback re the two patients:

Dad:

Dad is off the drip now and manages to eat on his own, even though it is a battle. The damage is severe and the assistant nurse told me yesterday afternoon his doctor wants to see me – they are nearly ready to discharge Dad, *but* ... he needs frail care. I have always believed Dad has the right to be home, and now we are faced with the decision of what to do. Not a decision I am going to take on my own – I just can't. But I must first hear what doctor has to say. And then I need to consult with my family – Sussa and Aunty M. And I must point out – I am anti-old age homes.

Alec:

He is still on a drip and on a regiment of antibiotics, anti-virals and anti-anything. Exceptionally restless. Same assistant nurse walked in on me yesterday afternoon when I read his file and instructed me to stop immediately. So I told her I will not, Alec is my husband and if she has a problem with me reading Alec's file, she should speak to Dr G about it. My response brought a complete change in attitude and won me a friend. Alec's Dr and I are talking about the road ahead for Alec and I wonder if it is deliberate that he scheduled his appointment with me straight after the therapist – he is aware that I see her today and they are colleagues.

Riatsila did a post on PML or Progressive Multifocal Leuko-encephalopathy which explains exactly what is wrong with Alec. Thank you Riatsila. What the piece failed to point out, though, is the speed with which PML can strike. Alec started showing symptoms the beginning of February, which we thought was a side effect of an antibiotic Alec took at the time. Little did we know that it would be downhill from there all the time.

Anne and I had a little meeting about Alec yesterday afternoon. Although he is my life partner, Anne is like a sister to him and I am not taking any decisions about Alec without running it past her. I do think Alec recognized her and Simmi last night when we visited. He did not recognise me the previous day though.

This photo of Alec was taken on the Sunday at Vic Falls. This is a typical Alec pose – carefree, full of life and full of joy.

Jessy:

Then feedback re our little Jessy. She is doing fine and recovering from her operation. She started walking around yesterday and is eating healthily. She does however, want nothing to do with Milo at all.

Aunty M and Sussa:

Sussa is back at work in full swing and that is her coping mechanism. She phones me every so often for feedback (about 6 times a day).

Aunty M appears fine, but deep deep down I know she is very hurt and anxious. She is very opposed, and understandably so, against Dad going to some place. I will make an appointment for her as well for counselling today.

The household:

Understandably, I am lethargic, listless and don't feel like doing anything at all. So big was my surprise when someone knocked on the door late yesterday afternoon with quite a few bags of frozen dinners. We are not needy, no, but it seems HeidiL realised somehow that I just don't get to everything and that food preparation is the last thing on my mind at the moment. So she order our local P&P to deliver an array of frozen dinners. *Thank you* Heidi – that was very thoughtful indeed – she even took cognizance of Aunty M's dietary requirements.

Myself?

I am hanging in there. I miss Alec immensely and I do tend to cry a lot. And then I go to hospital and I am completely a different person in front of Alec and Dad. Just to break down again when I walk out of there. It feels so unfair that this thing must happen to Alec and Dad and I battle immensely with that. Immensely.

I wish to thank each and every one of you who follows this drama in my life, who leaves a comment of support, who offers a prayer, who helps us, who sends me emails, who phones me, from the bottom of my heart.

Please *love your loved ones*. You know not how long you have the privilege. *Fact*.

Take care
Pieter

Notes: Understandably my recollections of these few days are vague, primarily because of all the angst I was experiencing.

I went to the therapist – lovely lady by the name of Madelyn Venter. Straight afterwards I went to see Dr Griffith to discuss the way forward regarding Alec's treatment. It was whilst waiting for him that I noted he was the chief medical officer of the hospital – it made me extremely happy to know that Alec was in good hands. Dad's doctor, Dr Swanepoel saw me before they could find Dr Griffith.

The feedback he gave me was that they had stabilized Dad's stroke but there was something else in his blood work that needed checking on. They thought that Dad might have a prostrate problem as well, as he had an exceptional amount of blood in his urine. He then went on to explain that when Dad was discharged, he would need full-time care. I was prepared to give that care, but I explained to him that I needed time before he discharged Dad, as I needed to train Heidi first to do my work. He pointed out that Dad would probably be discharged around the 14th or the 15th of April, which suited me perfectly. He also pointed out that Dad would probably need to wear adult diapers for the rest of his life.

After Dr Swanepoel it was time for me to see Dr Griffith and we had a good heart to heart conversation. He acknowledged my status as Alec's life partner, and I noticed some observations I made about Alec, which had not been mentioned on his observation sheet. He then suggested that should I notice positive (or negative) changes I should note it in Alec's file next to his own observations, as it would assist him. This became the way we remained in contact, without having to phone each other all the time.

The blogger named Riatsila, who had posted that hurtful post previously, now started leaving uplifting comments on my blog and even did a post about PML. His attitude changed completely. And it had me in better spirits.

Although Alec had not recognised me on the Monday, Tuesday or Wednesday, he recognised me positively that afternoon. At this stage his face was void of any expressions, in other words he could not smile anymore. He could, however react positively to a command. I asked Alec, that if he loved me, he should squeeze my hand. He squeezed my hand and then moved it to his face. And his face softened.

RTS sent me an email enquiring about Alec's PML. Here is our correspondence:

From: RTS
Sent: 03 April 2008 17:22
To: Pieter
Subject: Thinking of You
Importance: High

Dear Pieter,

Here I sit in Hong Kong thinking of you and Alec. I haven't had much of an opportunity to email you but I've finally caught up with things. I understand that the doctor thinks Alec has PML, has this been confirmed? Is this a fact? Are you sure? I can not tell you how I feel because words fail me. I only wish I was there – I feel so helpless here. How was your therapy session? Although I keep thinking of Alec, I am concerned about your well-being too.

I would very much like to see you again but understand that it is a difficult time for you. We'll be back on the 5th. Please let us know what else we can do to help – with regards to Alec and your dad.

As always, our prayers and thoughts are with you my friend.

Sincere regards,
RTS

From: Pieter
Sent: 03 April 2008 21:21
To: RTS
Subject: RE: Thinking of You

Dear RTS and Ramona
Yes, the doctor has now moved his opinion to PML. We can however always hope he is wrong, because it remains an opinion – it is not a fact yet. But it also does not help to kick against the prickles now – best to rather prepare ourselves for the worst. If the worst does not

arrive, well, then it is bonus time!!!! Fact of the matter remains that Alec is not responding to treatment as yet.

Alec had a very bad Monday, Tuesday and Wednesday in hospital. He was extremely restless. BUT we have him re-hydrated now, and today was the first full day that he was peaceful. He did not recognise me on Tuesday, but he did show positive signs of recognition yesterday and today.

His current Dr and I have an excellent working arrangement whereby we would leave each other notes in Alec's file. Also, on Tuesday next week Alec needs to see Dr Variava at Tshepong and they will transport Alec there and back and I get to go along. And of course, both consult with Dr S.

Therapy went okay. I declined antidepressants but kept my options open for a stronger tranquiliser than what I have as and when the time arrives that I need it. She is happy with the way I am coping with the whole situation, but she also stressed that I must look after myself and keep my reserves up. I am admittedly extremely emotional about Alec and scared sh*tless that I stand to lose him. I do not know yet how I will cope with that reality when it happens. However I try to take one step at a time, and allow myself to cry when the need to cry arises. As long as I am strong in front of Alec and Dad.

Re Dad – he might be discharged on the 15th or 16th if every thing goes according to plan. His Dr reckons that they now have the stroke situation under control, but that there are one or two other matters they want to have a look at whilst he is there and we await final results of tests they have done. Really, the service at Duff Scott is really exceptional and I am very pleased with both Dad's and Alec's doctors. They involve me in their treatment which empowers me tremendously.

Please don't feel that you can not see me because I am going through a difficult time. You'd brighten my day with a visit.

Enjoy your last day in Hong Kong!!!

Take care
Pieter

Friday

7:15AM, Friday, 04 Apr, 2008

Hi there

For some, today signals the start of the weekend. For me, it is just another day. Another day of wondering whether there will be improvement or deterioration. Yesterday was a day filled with hospital, hospital and hospital.

After my own therapy session I saw both Dad's and Alec's doctors. I have to admit that both doctors are extremely good and now involve me in their treatment plans. So herewith some feedback:

Dad

The stroke issue is under control now. They have however picked up something else that they want to treat while he is there and we will receive blood test results today or Monday and he will be treated for that (prostate) according to the results. His doctor said that it is unlikely that Dad will be discharged prior to 14 or 15 April. He did express concern about Dad's needs when he gets discharged, suggesting Dad to go into frail care, but not demanding it. After explaining that I will be looking after Dad as long as possible in his own home and that Heidi will see to my business affairs, he looked pleased.

Dad has sustained a lot of damage as a result of the stroke and some of the damage might not reverse itself, amongst it his speech. He will however receive intensive physiotherapy and has already started with it. More about this later.

Alec

His doctor says that he is not responding to treatment. He was extremely restless Monday, Tuesday and Wednesday. He did not recognise me on Wednesday, but yesterday he did. I told doctor about the recognition bits and he suggested that in a bid to help him, I must note everything I observe about Alec in his file. And if there is anything he wants me to have a look at, he will leave me notes in the file too. Yesterday Alec was much more calm and recognised me positively on both visits and even responded to one command **[dupl]** – I asked him if he loved me still and if he did, he should squeeze my hand, which he did. He is however still on the drip, and would be a while still.

My session

My therapist is of the opinion that, under the circumstances, I am handling the whole situation surrounding Dad and Alec well. One cannot take away the pain and anxiety, but one can learn to manage it. And the best way to manage it is not to fight it. So in front of Alec and Dad I remain strong and calm, but if I feel like cracking up when I walk out of there, I do not fight it and allow myself to cry us much as I want to.

My therapist is an occupational therapist/psychologist and works very closely with the physiotherapist as well. She said that she will be keeping an eye on Dad's physio for me and give me feedback on that, and will also see Dad for me prior to his discharge to evaluate if he is ready to come back home.

I am seeing her again on the 15th.

Other than that, there is no other feedback to give.

Take care, and for the Monday to Friday bloggers – have a good weekend. For the weekend bloggers – see you tomorrow.

Love
Pieter

Notes: A blogger by the name of Kosmos had left a comment suggesting Alec and I get married in hospital and a fellow blogger by the name of Iona (nowadays Butterbean) seconded that. It made me think. I had to give Alec something to cling onto, to fight for. I had to give Alec something to look forward to.

That afternoon I sat with Alec and held his hand and asked him if he could remember the 18th of June, the night we met. And then I spoke about our relationship and how happy we were. I told him how much he meant to me and how much I loved him. Then I told him that the moment he could say one clear sentence and fully regain his consciousness, I would arrange for a hospital wedding. A tear formed in his eye. And when I wanted to take my hand away, he grabbed it in both his hands and put my hand on his heart. I felt so proud of him that moment, my heart could burst. I stood like that for a long time.

Alec also lost the haunted look in his eyes. I felt really very bad for allowing him to dehydrate as much as he had, but I also realise it was unintentional.

Sitting writing this now, I realise that I have no recollection about Dad. Martie was there for him and I spent most of my time with Alec. I only greeted Dad, read his medical records quickly, then would go and check in on Alec and then go back to give Dad feedback about Alec.

What I do remember about Dad was that there was life in his eyes when I spoke about Alec and how it was going with him. Then I would return to Alec's bedside and spend the remainder of visiting hours with him.

I would sometimes just stroke his arm or his face or brush my hand through his hair. And he would make these mewling sounds, which I ascribed to pleasure. When I moved from one side of his bed to the other, or if I moved to the shelf where his medical file was, his eyes would follow my movements

Sideviews Weekend Challenge

2:18PM, Friday, 04 Apr, 2008

Describe your best winter's night – real or imagined.

Mine’s real.

It was Monday night, the 18th of June 2007. I went to Tlokwe to meet a man, whom I have met on an internet dating website. From the moment I saw him till the moment I left, we just could not stop talking. In between a friend phoned him – Anne – and said "Look out of the window". And there it was – Venus's occultation with the moon. I will never ever ever forget the sight. And somehow we knew – that night – we will be together for the rest of our lives.
That was the night I met Alec.
And I have no regrets.
Pieter

Notes: A fellow blogger by the name of Side View issues a challenge every Friday on her blog, for other bloggers to participate in. That week’s challenge fitted in with Alec and me so perfectly, that I decided to participate.
In a sense I am happy that I did not know what awaited us at that time.
Just as our first Christmas together would be our last, our first New Year together, would also be our last. Though I regret there was not more, I am thankful that I did not know at the time there wouldn’t be more.

Saturday

8:20AM, Saturday, 05 Apr, 2008

Good morning fellow bloggers

Yet another day. So here's the rundown.

Dad:

Looked very alert yesterday afternoon when we arrived. Almost glad to see us. The test results weren't back yet and the doctor answered the two questions I had left him, quite elaborately. Last night Aunty M could not go along as she was feeling a bit dizzy and her blood pressure was high, so it was only Sussa, me and a family friend Peter that went to visit him. He was heartsore that Aunty M did not go along. Knowing my Dad very well I am sure he is worried about things at home (amongst others Jessy – I have opted not to tell him or Alec about Jessy's miscarriage). But I know he would be worried about his cauliflowers, his broccoli's, the rest of the stuff. And every day I would try and assure him that everything is under control.

Alec:

Writing Sideview's weekend challenge yesterday afternoon opened up good old memories in my mind, which at the time of writing made me cry, but, I decided, I would share these memories with Alec and see how he would react. Kosmos has suggested a hospital wedding and Iona seconded that, so off I went to see Alec. Now first the physicals: the drip went into the tissue and his left hand was badly swollen. So I requested them to remove/repair it, which they did. Alec was very peaceful and I am very happy about that. He does not have that haunted look in his eyes any more, and his face is not as fallen in as it was when he got admitted to hospital.

So I sat with his hand in mine and asked him if he remembered Monday night the 18th of June, and retold him how we met. He got a tear in his eye. *Important* – he showed emotion. Then I gave him his challenge. I told him that I love him very much, and that if he could regain his awareness *and* regain his speech, we could get married right there in hospital. He did not squeeze my hand, but when I wanted to take my hand away, he held on to it and moved my hand to his chest over his heart.

See, I learnt a lesson yesterday: dream small and you will gain small. Dream big and you will gain big. And therefore I can give Alec a big dream to colour in whilst he is temporarily disabled.

Also of very big importance is that Alec started to eat again yesterday – okay, a liquid meal fed to him with a syringe, but it was the first "food" he'd had since admittance on Monday – which is encouraging.

Aunty M and me:

Aunty M and I work on a daily basis about her inability to "let go" of matters. Inherently she sees bad in everyone before she sees good and she continuously quotes from the past. So I made it my task to help her with that and rather see the positive in a situation and not the negative. And I think we made progress yesterday. she admitted on one occasion that I was actually right but that it is so difficult to let go. I admire her for trying. The stark reality of it all is that now that Dad and Alec are both in hospital we are forced closer to each other and I am the only company she's got. I regard this as quality time in which we can mean a lot for each other and help each other. And I dare say I am making progress.

Jessy:

On her second last day of antibiotics and running around boundlessly. Had a scare yesterday but it is all sorted now – she bent down as to widdle, but nothing happened. Ran a few steps, bent down, nothing. I watched her closely but after about the 5th time, she did manage to get out what she wanted out. Kept an eye on her for the rest of the day, but it appears normal now.

So there you have it.

Apology time: I am really sorry if I do not respond to each of your comments. I am sure that you do understand. Each one is read, appreciated and savoured though. And I say thank you for that. I am deeply humbled! I receive emails from as far as Utah, the UK, Germany and Canada – from complete and utter strangers. From South Africa I receive emails from people saying thanks for what our situation means to them, and that it actually brings them and their loved ones closer to each other. In another instance, it appears to be of help to a person who lost her husband some years ago under more or less similar circumstances. Perhaps all of this is happening so that others can draw strength from it.

So, without sounding rhetorical at all, here we go again – *love* your loved ones. Appreciate them. For you do not know how long you will have them with you. *Fact*.

Love
Pieter

Notes: I remember the e-mails and even phone calls I received – not only from within South Africa, but also other parts of the world. These emails included: Rene and Trevor K in Utah, Marcy in Germany as well as Nur Ich in Canada. All these were emails of support and encouragement.

During the time both Dad and Alec were in hospital, I remember Martie and I were forced to work together and stand together. It was actually through Grace from Above that we were able to get along relatively well, because keeping Martie positive was no easy task. I constantly had to remind her not say anything negative in front of Dad. I had to try and steer her negative conversation to a more positive conversation. I asked her not to get upset about Dad in front of him. I told her she could take out all her frustrations on me after we had left the hospital, but while Alec and Dad were in hospital she had to fight her emotions and remain strong.

Saturday – 2

1:53PM, Saturday, 05 Apr, 2008

Hi there Bloggers

Had a brief word with Alec's doctor this afternoon and he says he is encouraged by Alec's progress. Good sign?

Spent most of my time with Alec this afternoon and less with Dad. Pieter is on a mission for signs of improvement and so set out on asking Alec questions to which he would only have to nod yes or no. Of the five "yes" questions I asked, I got five small yes nods. But I did not get a no nod for the no questions I asked him, though I did not get a small yes nod either. Will continue with this again at the next visiting hour. What *was* encouraging though was to observe that he took his meds without a syringe.

I did make sure that I gave Dad this encouraging news about Alec so that his mind can be put to rest about it at least. From where Dad lies, he can see Alec. Initially I thought it might not be a good idea, but I have changed my mind about it. At least he can see that I am still there, whilst Aunty M is tending to him. Then about half way through we change for 5 to 10 minutes and then we change back again.

Dad is progressing "well", I think. He wants to handle his water bottle himself and gets uptight if you want to help him. Good sign – I think.

Will this sad state of affairs have a happy ending after all? I certainly hope so.

Love
Pieter

Notes: When we arrived at the hospital that afternoon for visiting time, I saw Alec's doctor walking back to his car. We chatted briefly for a few seconds and the doctor seemed positive about Alec's treatment. He also reminded me that I had to be at the hospital early on the morning of the 9th, as Alec would have to be transported by Ambulance from Duff Scott to Tshepong for a follow-up with one of his specialists there, and I would have had to go along.

The previous day they moved Alec from one of the isolation wards to a ward right across from where Dad's bed was. At first I had been opposed to it, as I was afraid that the sight of one seeing the other might have a negative impact on their mental well-being. I realised that afternoon however, that perhaps it was a good thing, because then Dad could at least still see me when I was with Alec, and I hoped that thought would comfort him. I somehow doubt that Alec could see Dad.

I also felt very positive about Dad attempting to hold the plastic drinking bottle to his mouth and trying to sip from it himself. It was really encouraging to see him do that.

Sunday

8:33AM, Sunday, 06 Apr, 2008

Morning All

Just a short note to say all is stable. Alec did not respond to yes/no questions last night, though he thoroughly enjoyed it when I washed his face. He made little moaning sounds. And when I read him I Corinthians 13 (our favorite piece), he became so immensely calm.

Dad's doing fine and the night sister in charge told me that was it not for the additional blood tests for his prostate, he would have been able to come home already. I'd rather have them check out his prostate thoroughly and make sure that everything is in order, than have him home. Also – I need at least one full day with Heidi to show her the ins and outs of my business and how to quote, etc., before I can let Dad come home because when he does, I know we will have our hands full.

Regarding Dad – in a fit of creativity, I conjured up a way for Dad to communicate with us. Fridge magnets with words on them. Or little cue cards with pictures on, for instance a roll of loo paper could indicate he wants to go to the loo, or a picture of a cup of coffee could indicate that he wants a cup of coffee? Any other creative ideas out there? To be honest, communication (and more importantly understanding Dad) is going to be our biggest challenge.

Have a full house today. Anne and Simmi are coming over, as well as Sussa, and I am also preparing for a surprise guest or two.

So without further ado, let me bid you adieu and wish you a stunning Sunday.

Take care – And remember: *love* your loved ones. Why? Because you never know how long you have them for – *fact!!!* And I know this is going to sound boring, But I will remind you of it every so often. Okay?

Love
Pieter

Notes: I don't know what I would have done without Annemarie, Simmie and Joey. The three of them were such huge pillars of strength in this very trying time. Annemarie came through as often as she could, and Joey and I were in constant contact. Duff Scott Hospital had three sets of visiting hours on a Sunday, 11:00-12:00, 15:00-16:00 and then again from 19:00-20:00. We decided this day that we would skip the 15:00 visiting hour, all go together at 11:00 and then come back home to a proper lunch, a decent meal, something that Martie and I had not had in days. I was also quietly expecting RTS and Ramona, but unfortunately they were unable to make it, as RTS celebrated his birthday and they had just arrived back from the Philippines.

I realised that communication with Dad was going to be a problem when he was discharged from hospital. And we racked our brains for ways to make it easier for him to communicate. I had the idea of laminating pictures of objects Dad would generally use – like a cup of coffee. I discussed this idea with Joey and she liked it. We decided that in the following week, we would find suitable pictures we could use to make communication cards for Dad.

I also discussed with Joey, changes I needed to make inside the house to make it wheelchair friendly, as it was evident that Dad would require a wheelchair upon his discharge.

What worried us that day was that Dad was very tearful and looked sad. I was worried that Dad was becoming depressed because he had realised the implications of his stroke and the impact it would have on his life.

Monday Monday

8:11AM, Monday, 07 Apr, 2008

Good morning all

Another day, another week.

Without any further ado – feedback:

Dad:

Yesterday Dad looked a bit down and a call to the ward this morning resulted in them informing me that Dad is not well. He was a bit tearful yesterday and I suspect that it might be the onset of a depression, brought on by the stroke and the subsequent discovery of a prostate problem. I hope the doctor gets the results today.

Alec:

Did not respond to any yes/no questions yesterday. However, during the afternoon the Sister asked me if I wanted to feed him some soup and Alec had a whopping 60ml by syringe. I tried the spoon first but it did not want to work, *but* I saw immediately that he does want some (he started chewing actions). He also made this low moaning noises as if to indicate that he is enjoying it. During last night's visit he was very comatose; but that is because they had just administered medication by drip which kind of knocks him out. With Alec it is baby baby steps. But, I am excited about the progress so far.

The household:

This week will consist of preparing Heidi's room, getting rid of unwanted junk and getting the house wheelchair friendly for when Dad returns. Ah, plus a fight with our ward councillor, because the street light in front of our house has been out for the past two weeks and I have reported it out of order four times already. It is so dark when you get back home from hospital, that I just can not afford to have it out of order.

And that is my very brief feedback.

Have a good day – and remember – *love* your loved ones. You know why.

Love
Pieter

Notes: The Monday and Tuesday are a bit blurry for me. There was the discussion with our ward councillor – I remember that. Our street light had been out of order for some time, and no matter how many times I reported it, it just did not get fixed. Our ward councillor had a reputation of getting things done, so I resorted to this method to get our street light fixed.

I also remember a very close friend of mine, Pieter du Toit, came over to visit that night, after I had already locked up everywhere – including the security door in our passage. I unlocked the door and put the key down on the showcase in the passage. Big mistake. I should have hung it back on its usual place.

I did however, enjoy Pieter's visit immensely. We chatted about Alec and Dad and the way forward once they were discharged.

Tuesday

11:56AM, Tuesday, 08 Apr, 2008

Good day all my blog friends

Thanks for all the comments yesterday. You probably wonder why I was so quiet this morning – well we had drama here that's why. We have installed a security door in the passage some time ago. Late last night one of friends paid me a visit, and I unlocked the gate and took the key with me to the front of the house, where I left it. And after he left, yep, I locked the gate!!! Now we do have a spare key stashed away somewhere in Dad's room, and it took me over two hours to find the damn thing. Aunty M and I had a good chuckle about it.

Both Dad and Alec were very comatose yesterday. If Alec was awake for 1 minute during the time I was there, it was a lot. Same with Dad. And last night the same thing again. Phoned early this morning and according to the staff their condition is the same as yesterday. So we will see this afternoon how it goes.

In regards to tomorrow – I have to be at the hospital at 06:00 because I am going with Alec in the ambulance to MTM hospital 1 for a follow-up visit with his very first doctor. And I *do* have a lot of questions to ask him. So I will only post an update upon my return and we do not yet know what time that will be.

So in the meantime – keep safe and *love* your loved ones.

Love
Pieter

Notes: I turned over Dad's room looking for the spare key to the security door in the passage. Dad told me when we installed the security gate that he was going to put one of the set of keys in the safe. But it was not with the keys that were lying separately in the safe. I turned over his wardrobe, his drawer of his bedside table, looked in all his pockets of all his clothes.

The third time I went through the safe, I decided to check in some of the boxes that had some of Martie's possessions in. I found the key I needed in one of those boxes. So Dad was right – it was in the safe after all. The cup of coffee I made myself after being able to get to the kitchen was probably the nicest one I ever had.

Tuesday night

7:42PM, Tuesday, 08 Apr, 2008

Hi there

Allow me to wallow in my own shit for a minute. But yesterday and today were not good days for me. Not because Alec is bad, but because I am despondent. I am alone, I miss Alec, and I miss us. I cry at the drop of a penny and see anything Alec and I have done together in everything I see. Name it, and I will be able to recall something that Alec and I have done together.

Okay – enough wallowing.

Dad was much better today. Alec has been as unresponsive as yesterday. I held his hand a bit, managed to kiss him hello and goodbye (but it did not register with him) and that was it. Had a long chat with Dad's doctor. They are concerned about his prostate at the moment, *but* he feels that now is not a good time to do a biopsy on Dad – he will not handle the narcosis very well. The blood test results did indicate a problem. We will wait on this for a while and then perhaps we can do the biopsy. Otherwise all indications are that Dad will be discharged next week. I asked his Dr not to discharge him before Wednesday. it gives me two full days with Heidi to teach her everything there is to know about my business.

Alec is all prepared for tomorrow morning and I have been reminded to be there at 6. I hope that the Dr will be able to give some answers – I have a myriad of questions.

Any case – let me go to bed – I think tonight I will take a tranquiliser – I am extremely tearful and don't need an excuse for crying. It happens sommer by itself.

Love your loved ones. And sommer for my part too. okay?

Love
Pieter

Notes: I was missing Alec. In hindsight I must have begun accepting the inevitable.

Alec was very unresponsive during those past two days, to the point where I doubted he recognised me. But what got to me was that here was this man lying in bed, not knowing what was going on around him. Or did he know? Was he comfortable? What else could I do to make him more comfortable?

And frantically I read from 1 Corinthians 13 when I visited with him, I would pray that God would heal him. Or His will be done.

Wednesday – Final Diagnosis

1:25PM, Wednesday, 09 Apr, 2008

Final diagnosis: Progressive Multifocal Leukoencephalitis
Prognosis: anything from 1 hour to 4 months
Treatment: Hospitalisation and specialised nursing care

That's me for the day.

Love your loved ones.
Pieter

Notes: I went to the hospital at 05:30 that morning, waited for Alec to be moved from his bed to a stretcher, then covered with a blanket and then transferred to the waiting ambulance. Duff Scott is regarded as a step down facility, so whenever patients who have been admitted there need to see a specialist, they are transported from Duff Scott to either Klerksdorp hospital or Tshepong hospital, depending on what condition the patient had. HIV patients were normally referred to Tshepong. After consulting with the specialist, the patient would then be taken back to Duff Scott.

Duff Scott sent a male nurse along with Alec and me to Tshepong. The three of us waited over two hours to see Alec's original specialist. I would sometimes leave Alec with the nurse to go outside and have a cigarette. Then I would come back and sit with Alec. He was very restless and would pull his left leg up. Because the stretcher was so narrow, I was scared at the time that his leg might drop to the side causing him to fall off the stretcher.

The specialist eventually arrived, and mentioned that he was aware that we had been to see Dr S. He did it in such a way that I got the impression that he thought I doubted his opinion. I explained to him that we had a benefactor who had been prepared to pay for a second opinion. We then went briefly through what Dr S had said, and then this specialist described to me the lesions he had observed on Alec's brain.

There was a big lesion on the right hand side of his brain and a smaller one on the left hand side. The lesion on the left hand side of his brain had affected his motor movements, which was why Alec only lifted up his left leg and not his right leg. He has lost the ability to use the right side of his body. To prove this to me the scraped his car key along the sole of each of Alec's feet. When he scraped the right sole, Alec did not pull his foot away, but when he scraped Alec's left sole there was an immediate reaction.

The specialist then said that Alec definitely had PML, and all we could do was pray for a miracle and keep him as comfortable as possible. I asked him about possible treatments such as Cidofir, to which his response was: “What more do you think we can do that they cannot do at Duff Scott?”

I was fighting back the tears, but I did not succeed. He then asked me to come through to his consulting room so that he could write Dr Griffith a note. The paper he used was the back of a recycled page. He scribbled a few short notes, the latest CD4 count that they had taken, and his viral load. He then wrote the words: “Prognosis: Guarded” on the piece of scrap paper.

Consultation over, we waited for the ambulance to come and fetch us again. I remember leaving Alec with the male nurse to go and stand outside for a cigarette. A woman who had come in earlier to the casualty ward joined me outside and asked if she could have a cigarette. I remember just staring blankly in front of me whilst I handed her one. She then asked if my friend was very ill. I said in a flat but quivering voice: “He is busy dying.” What I wanted to do was scream at her: “What fucking business is it of yours!!? Leave me alone!!”

The ambulance arrived about an hour and a half after we phoned them to say we were ready to go back to Duff Scott. In the back were four African males. I remember them staring at me and Alec. I wanted to scream at them: “What the fuck are you looking at?” But I just allowed the tears to flow down my cheeks. One of them touched my arm and said: “It’s okay to cry.”

We drove in silence back to Duff Scott. Alec’s last road trip.

When I got home later, I just fell down on our bed and cried. I arranged with the neighbours across the road from us to take Martie to the hospital to visit Dad. I did not go back to hospital that day.
I was too exhausted.

Too drained.
Too torn up.

Know your status

7:23PM, Wednesday, 09 Apr, 2008

No need to pussyfoot around anymore. Alec – *if ever ever ever* you read this, please know that I did this post as a warning to others, so that others could learn from your situation. *Know your status* folks, *know your status*.

All of a sudden Alec started doing funny things. You ask him for a plate and he gives you a saucer. You ask him for a spoon, he hands you a fork. And in his case, he started to stutter. All of this one bright and sunny February day. *This is how PML starts!* Be aware!! The sad fact is – it is not AIDS, but an opportunistic disease. Nine out ten people carry the JC virus in their bodies. It resides in your kidneys. *Only* when your immune system becomes impaired (either by HIV, an organ transplant, serious antibiotics), this virus starts creating havoc. And rapidly so!!!

Alec's PML Timeline

Beginning of February: Alec starts complaining about stuttering
18 February: Alec has an attack at work that looks like a stroke
19 February: Dr at MTM1 says Alec must go for a C/T scan
20 February: We discover Alec tested HIV+
21 February: I test HIV- (Have to do follow-up 21 May)
25 February: Alec has his C/T Scan. Dr at MTM says Alec had a multiple Infarct – series of small strokes over a period of time. He is admitted to hospital.
27 February: Alec goes for an MRI scan. I read the report that night saying that he has lesions consistent with PML on his brain
28 February: Specialist at MTM1 informs us of Alec's possible diagnosis of PML

29 February: Alec starts HAART (Highly Active AntiRetroviral Treatment). Dr mentions there might be a second possible diagnosis because his CD4 count came back high.
05 March: Alec discharged
10 March: Alec starts to deteriorate
15 March: We are supposed to get married.
19 March: Alec sees Dr F. He refers us to Dr S, who is the leader in the field of HIV neurological disorders
25 March: Alec sees Dr S. I started feeding Alec a day earlier with a syringe. Situation deteriorated even further
28 March: Alec moves over to Diapers
01 April: Alec admitted to MTM2 (which is like a 5-star hotel compared to MTM1)
09 April: PML Confirmed. No reaction from his right side of his body. This is the third day in a row that he has not recognized me. Dr says: "Nothing more we can do but pray for a miracle". Hard words. I'll never forget them. Ever.
10 April: ??? There is no cure and no treatment for PML other than what Alec is on. He might react to it, he might not. Odds are not, because he has been steadily deteriorating. By now, we would have hoped to see an improvement.

Now – for the record: If *anyone* makes a snide remark about Alec being HIV+ you better pray to God that I do not find you. I fell in love with Alec because of him. Who he is. I did not walk around with an advertisement reading: "Only HIV- need to apply". In fact when I was lonely and single, I prayed to God and *asked* him to send me *someone* – even if he is HIV+. I have posted this post because someone out there might not know their status, or might experience similar happenings. This post serves to help *those* people. I have thought long and hard about this – I wanted to start to second blog aimed at counselling about HIV. I will however continue to do this under Jessy's brand.

As for me, how do I feel? Of course I am hurt. Of course I am sorry for myself. I am sorry for Alec. He is so loved that my Dad went and had a stroke because of my suffering with Alec. A double blow for me. *Wow*. I am seen as this “strong” person. I’m not. I can assure you though – Alec will *always* be my sweetheart. And *no-one* will fill his place. We will be together, forever, and always, even if death parts us 20 years apart.

Let us start a legacy for Alec: LYLO. Love Your Loved Ones. I beg you, from the bottom of my heart. You just have to look at the above timeline to realize how quickly things could happen. And that is slow – it could be a car accident?

LYLO
Pieter

PS: For those who do have my telephone number – please do not call me now. I need some Pieter time. I need to cry and cry and cry. Life is unfair. And right now I have to deal with it. So please respect my me-time.

Notes: The comments I received on my previous post were overwhelming and extremely supportive. That afternoon I decided to break my vow about Alec’s HIV status and revealed it on my blog. I did it, because I did not want anyone else to go through what I was going through. I wanted to make people aware of what could happen if you are HIV + and leave it undetected. I did not do it to label Alec. I was scared of negative comments but received none. What I did receive was love and support from a blogging community where everybody is more or less anonymous.

It was also the start of LYLO. The acronym for Love Your Loved Ones.

The same line I ended most of my posts with since Alec fell ill. LYLO just came to me and I made it Alec’s legacy. I created it for Alec. The man I loved so much who was now dying.

A fellow blogger, DT, immediately created a badge – and most of my die hard followers copied this badge onto their blogs. Most of those bloggers still carry the badge on their blogs.

Thursday morning

8:31AM, Thursday, 10 Apr, 2008

Good morning all

Understandably I have been down and out yesterday. I was hopeless, heartsore, angry, defeated, depressed. To the extent that I opted not to go back to hospital yesterday afternoon or evening. Our neighbours took Aunty M to see Dad, and his condition is still the same.

Somewhere during the course of the night I got an email.
Darling Pieter,

I'm so sorry. I don't know what else to say, other than "Let's keep going!!"

We will continue to pray that the treatment works, there have been cases where it does. In the mean time, XXX will get hold of Dr. S, and see if we can get hold of any trial medication either here or abroad. If you have any info that could be helpful in our search, please let us know.

In the mean time Pieter my darling, keep the faith. We will *still* do everything we can from our side.

We love you Pieter. Please remember that. We do not wish to intrude on you at this point in time, but beg you to call us when you need us. We're only a phone call away.

Please check out the articles that I have pasted below, regarding a drug mixed with HAART for PML. Pay *special attention* to number 2! Have you heard of it? *Please* let me know. We are still going to the end of the earth for Alec.

Loads of Love,

XXX & YYY – Your friends no matter what.

Turns out that there is a drug, let's call it Drug A, that has been used with some success in the USA for PML. In one case, a man that has been diagnosed with PML and could neither walk nor speak, was able to do so after one week of taking this drug!!!

PROBLEM:

This drug is NOT available in SA and therefore not tested. I am having a meeting with Alec's doctor today to find out what we can do about it. My friends are just waiting for my call to import this drug from America – they have already done all their research and I have done my research from 05:00 this morning about this drug. My argument is this: if Alec's attending specialist gave him the death sentence yesterday, (his words were "What else do you think there is that we can do here at MTM1 that they can not do for him at MTM2? All we can do now is hope for a miracle and provide Alec with the best nursing care to make his last days as comfortable as possible"), we have nothing to lose. Absolutely nothing. And if it could benefit someone else besides Alec, we have done a major service to this country.

So, dear friends – let us hope. Let us pray that bureaucracy will not stand in the way of potential improvement.

LYLO
Pieter

Notes: I remember I was over the moon when RTS and Ramona sent me this email. It was about a "drug" called Peptide T. I hyphenate "drug" because it is not a drug per se, but an Amino Acid. It has no side effects and has been proved in the USA to have some success against PML. I remember scouring through every possible website to see if it was registered in South Africa, but could find nothing. I scoured university websites, research institutions, and the Medical Council's website – to no avail.

I remember making an appointment with Alec's doctor, so that I could discuss this medicine with him. During this meeting I learnt what the prognosis "Guarded" meant. In doctor's terms it means "just a matter of time". We spoke at length about the medicine. I gave him all the information I had on it. He was very sympathetic about the whole issue and explained to me that he understood that I am in dire straits, but even if we should get the medicine and it is not registered in South Africa, he would not be allowed to administer it.

And then he said something that gave me the greatest respect for him. He said that nothing could prevent me from administering the drug to Alec. Thus, RTS, Ramona and I decided that we would import Peptide T into South Africa and I would administer it to Alec once it arrived.

South African ex-pats in the USA offered their assistance in purchasing the Peptide T and sending it on to South Africa to me.

When I told Alec about this, I could see relief in his eyes. There was a shimmer of hope, and that gave me hope too.

RTS and Ramona researched companies that sell Peptide T to see if they would ship it to South Africa. We discovered that the problem would not so much be purchasing the Peptide T, but more in getting it into South Africa. Some of our correspondence of that day:

From: Ramona
Sent: 09 April 2008 22:33
To: Pieter
Subject: Peptide

Pieter,

They DO ship this **Peptide T** to South Africa, RTS is creating an account right now to see if we can arrange it. PLEASE! As soon as you can, let us know what to do??

From: Pieter
Sent: 10 April 2008 06:01
To: Ramona
Subject: RE: Peptide

Hi there RTS and Ramona

As I said yesterday to RTS – Dr Luke has given up on Alec. My opinion is if it could help someone else than Alec, so be it; let Alec then be the guinea pig. Sounds harsh but that is how it is. I will seek an appointment with his attending doctor today still.

Many many many thanks – will let you know the outcome ASAP.

LYLO
Pieter

Friday

7:48AM, Friday, 11 Apr, 2008

Hi there all

First of all thanks to DT for creating the excellent LYLO badge and to those who already have it on their blogs. Thanks also for all the comments of support, comfort and just a "hi".

I don't really think anyone can understand the immense highs and immense lows one goes through in a situation like this. For instance, for 4 days in a row Alec has not recognised me, in fact he was lying so still yesterday afternoon that I really thought the end is very near. Then yesterday evening he recognised me and even attempted a smile!!

Same with Dad – for three days now he looked lethargic and had this strange blueish colour in his face yesterday afternoon. And then last night, he looked radiant and quite frankly beautiful. He held my hand so tight and shed a tear or two. Aunty M could not make the visit last night as she did not feel well (she worries about everything and if there is nothing to worry about she worries about that too – said with the greatest love and respect). Two of my and Alec's friends picked me up and they visited with Alec and I visited with Dad. So for the first time since he was admitted to hospital we were alone, and I could say some things to him that belong between him and me. Explained to him that all is well at home and everything is taken care of. Told him that his condition is improving but that he must cooperate if he wants to get better – that I understand that it is a shock for him to be in this condition and that no-one wants to be in it, but that the more you kick against it, the longer the healing takes. That he must remember that when I was a baby and helpless, he looked after me, and now that he is elderly and in his condition, it is time for me to return the favour. And during this conversation he just clung to my hand. Ah, and I fed him some soup! We are concerned about his food intake and prepared some soup to take along. He ate well last night.

Alec: Well P&JJ reckon Alec recognised them. P made sure that he moved around the bed to see if Alec "follows" him, which he did. So here's to hoping.

Now you ask about the medicine for Alec. I can not reveal too much about it at this stage. Alec's Dr and I had a chat about it and the long and the short of it is that if the meds are not registered in SA, he may not administer it. Period. He did indicate however, that he can not prevent me from administering it ... And that is where I am leaving it for now. Intense internet searches has brought us on the doorstep of a company in SA that *might* have this medicine and that it *might* (read slim possibility) be registered as an experimental drug, which would be very good news indeed. If not, read the section preceding the periods. In this regard – thanks to so many people who has contacted me already offering help and support. One of our new friends in Utah has already emailed me with her address and offer of help in getting the drug from the USA to SA – you can buy it over the counter there. There are countless other offers that sprung from this and I wish to thank everyone for that.

So that is me for today - have a fab one and hold thumbs for that drug.

Take care and remember – LYLO
Pieter

Notes: I remember feeling a little more upbeat after our visit to Dad and Alec the previous evening. Pieter and JJ took Alec a purple slipper orchid. I spent some time with Dad on my own whilst Pieter and JJ visited with Alec.

Little did I know that this would be my final visit with Dad, on my own.

Some time during the course of the morning I discovered an article on the internet dealing with Peptide T as a possible drug to be used against PML. I forwarded this article on to RTS and Ramona in the following email:

From: Pieter
Sent: 11 April 2008 09:20
To: Ramona
Subject: Method of treating neuroinflammatory degenerative diseases

An Article I found on Peptide T that is a bit more positive than the one you just sent me. Love

Pieter

Method of treating neuroinflammatory degenerative diseases

US Patent Issued on April 14, 1998

http://www.patentstorm.us/patents/5739109-description.html

Description

TECHNICAL FIELD

This invention relates to the treatment of neuroinflammatory degenerative diseases and more particularly to neuroinflammatory degenerative diseases which are cytokine mediated.

BACKGROUND OF THE INVENTION

Progressive multifocal leukoencephalopathy (PML) is a rare afebrile demyelinating disease of cerebral white matter characterized by multiple, discrete foci of disease. A papovavirus, JC virus, is consistently identified in oligodendrocytes in affected areas, and is believed to be one cause of PML. The symptoms of PML include headache, ataxia, hemiparesis, confusion, and other mental status changes. Computed tomography scans most often reveal nonenhancing, low-density lesions of the periventricular white matter. Magnetic resonance imaging scans show high-signal intensity lesions without enhancement. Cerebrospinal fluid studies are usually unrevealing; the diagnosis is established by brain biopsy. JC virus can be identified by typical electron microscopy morphology, by immunofluorescence staining, or by gene amplification techniques. Clinically, patients deteriorate progressively. Death occurs on average in less than 3 months, although spontaneous remission has been reported.

JC and BK viruses (JCV and BKV) are human polyomaviruses. Infections with these viruses appear to be widespread, but asymptomatic in the majority of patients. JCV or BKV infection apparently is acquired during childhood and persists in the kidney. Approximately 60-80 percent of adults in the United States and Europe have antibodies to JCV and/or BKV. However, the incidence of HIV infection has significantly altered the epidemiology of PML.

In the pre-HIV era, PML was seen primarily in older patients with underlying hematologic malignancies. PML was also sometimes seen in patients with other causes for depression of cell-mediated immunity, such as steroid use. Rarely, patients have been described who developed PML in the absence of any identifiable immunodeficiency.

Reported deaths due to PML have significantly increased with the rise in AIDS cases, from 1.5/10,000,000 persons in 1974 to 6.1/ 10,000,000 persons in 1987. It is estimated that over half of the deaths due to PML are associated with HIV infection and that approximately 1-4 percent of patients with HIV infection will develop PML.

The neuropathologic findings of PML are most likely a result of direct infection of the oligodendrocytes with JCV, leading to decreased myelin production and demyelination. Electron microscopy and in situ hybridization have been used to demonstrate the presence of polyomavirus in oligodendrocyte nuclei. BK and JC viruria can be seen in patients with a variety of immunodeficiencies, but appears to be most frequent among renal and bone marrow transplant recipients. In addition, pregnant women may excrete JCV or BKV in third trimester, perhaps related to defects in cell-mediated immunity observed during pregnancy.

Newer research strongly suggests that PML is in large part an inflammatory disorder. Accumulating evidence shows that adhesion molecules are critically involved in inflammatory demyelination in the focusing of systemic immune responses into the target issue, the nervous system. Adhesion molecules are unregulated through the action of cytokines, a heterogeneous group of human proteins that are active at low concentrations to regulate cell growth, differentiation and function. Tumor necrosis factor alpha appears to be of prime importance.

Circulating adhesion molecules probably reflect acute inflammatory episodes in the central and peripheral nervous system, but may also function to modulate ongoing inflammatory responses. Cytokines released by THI cells render resident and immigrant macrophages, as well as microglia, activated to synthesize and release increased amounts of inflammatory mediators, such as oxygen radicals, nitric oxide metabolites, and components of the complement system. A more detailed understanding of the sequence of immunopathologic events that culminate in myelin damage in the central and peripheral nervous systems has revealed several sites to which more specific and effective immunointervention can be targeted.

Cytokines participate in normal physiologic events within the central nervous system. At time of infection and inflammation, their role is emphasized by the unregulation of cytokines and their receptors within the central nervous system, with concomitant effects on brain function.

Cytokines produced by glial cells, T cells, and macrophages interact within the central nervous system to determine the outcome of the inflammatory reaction. Cytokines have been implicated in the pathogenesis of many neuroinflammatory degenerative diseases, including multiple sclerosis (MS), and amyotrophic lateral sclerosis (ALS), as well as PML. Though no link has been made, their role continues to be intensely investigated.

The microglial cell is the central nervous system representative of the peripheral macrophage. The central nervous system is far more sensitive to immune inflammtory modulators which probably are practical responses to toxins, tumors and infections. It is when these inflammatory modulators are dysregulated in these diseases that true damage through demyelination and neuronal growth toxicity may occur.

Treatment of cultures of myelinated cells with inflammatory cytokines results in a marked reduction in myelin based protein. Microglial reactive damaged nodules are clearly evident and a characteristic of PML. Normal brain sections show no reactivity for any of the cytokines while PML tissue demonstrates the clear presence of at least IL-6, TNF, and interferon-gamma. Inhibiting specific cytokines and forms of mitogenesis may also act to stabilize activation of virus and protect the host from immune mediated damage induced by the virus or its products and/or effects.

Peptide T is a short peptide fragment capable of blocking the binding of gp120 to neurons or lymphocytes. This blocks entry of virus into a cell through CD4 receptors and blocks the toxic effects of gp120 on specific types of cells and tissues.

DESCRIPTION OF THE INVENTION

Described is a method of treating neuroinflammatory diseases which are cytokine mediated in which a person suffering from such a disease, for example, PML, is administered a therapeutically effective amount of a peptide of the formula:

R^a -Ser-Thr-Thr-Thr-Asn-Tyr-R^b (I)

where R^a represents an amino terminal residue Ala- or D-Ala- and R^b represents a carboxyl terminal residue -Thr or Thr amide, and/or an additional Cys-residue at one or both of the amino and carboxyl terminals, or a peptide of the formula:

R^1 --R^2 --R^3 --R^4 --R^5 (II)

where R^1 is an amino terminal residue Thr-, Ser-, Asn-, Leu-, Ile-, Arg- or Glu-; R^2 is Thr, Ser or Asp; R^3 is Thr, Ser, Asn, Arg, Gln, Lys or Trp; R^4 is Tyr; and R^5 is a carboxyl terminal amino group, a corresponding D-amino acid as the amino terminal residue, and/or a corresponding amide derivative at the carboxyl terminal residue and/ or additionally a Cys-residue at one or both of the amino and carboxyl terminals, or a physiologically acceptable salt thereof. Also the peptide may have the formula X-R^1 --R^2 --R^3 --R^4 --R^5 -X, where R^1 -R^5 are as defined above and X is cysteine.

Preferred peptides are

ala-ser-thr-thr-thr-asn-tyr-thr, thr-thr-asn-tyr-thr,

ser-ser-thr-tyr-arg, asn-thr-ser-tyr-thr,

thr-thr-ser-tyr-thr, ser-ser-thr-tyr-arg,

asn-thr-ser-tyr-gly, ser-thr-asn-tyr-arg,

ser-ser-thr-tyr-arg, ser-ser-arg-tyr-arg,

ser-ser-thr-tyr-arg, thr-thr-ser-tyr-ser, and

cys-thr-thr-asn-tyr-thr-cys.

The peptide is preferably conjugated to a protein, such as human serum albumin. Preferably, the peptide is ASTTTNYT, also known as Peptide T.

The selected peptide is administered in a therapeutically effective amounts that is an amount sufficient to diminish, halt or to reverse the patient's loss of function due to neuro-inflammation. Usually, the amount administered is an amount of from 0.2 to 50 mg, preferably 0.2 to 30 mg per day for a 70 kg adult human. The peptide may be formulated for oral, buccal, parenteral, topical, intranasal or rectal administration.

Also disclosed is a method of arresting the degeneration and loss of cerebral function in a person having a neuroinflammatory disease which is cytokine mediated comprising administering to that person a therapeutically effective amount of a peptide of the formula:

R^a -Ser-Thr-Thr-Thr-Asn-Tyr-R^b (I)

where R^a represents an amino terminal residue Ala- or D-Ala- and R^b represents a carboxyl terminal residue -Thr or Thr amide, and/or an additional Cys-residue at one or both of the amino and carboxyl terminals, or a peptide of the formula:

R^1 --R^2 --R^3 --R^4 --R^5 (II)

where R^1 is an amino terminal residue Thr-, Ser-, Asn-, Leu-, Ile-, Arg- or Glu-; R^2 is Thr, Ser or Asp; R^3 is Thr, Ser, Asn, Arg, Gln, Lys or Trp; R^4 is Tyr; and R^5 is a carboxyl terminal amino group, a corresponding D-amino acid as the amino terminal residue, and/or a corresponding amide derivative at the carboxyl terminal residue and/ or additionally a Cys-residue at one or both of the amino and carboxyl terminals, or a physiologically acceptable salt thereof, and continuing the administration on a maintenance basis to prevent or diminish further degeneration of cerebral function.

Preferably, the peptide is administered in an amount such that demyelinating of the oligodendrocytes, macroplates and microglia, is at least reduced or stabilized, the peptide acting as an anticytokine modulator to stop the effects of the inflammation, even in the continued presence of the virus.

While not wishing to be bound to any particular theory or mode of operation, the short chain peptides described herein, notably Peptide T, are believed to inhibit cytokines to stabilize activation of the virus and protect the host from damage.

Peptide T may be potentially of significant benefit to the host in preventing disease progression through mediation of viral and dysfunctional immune activation. It is theoretically possible that an uneasy truce may be maintained with viral presence without further damaging the host.

Peptide T may regulate a turned on immune system which is damaging itself through its friendly fire inflammatory response. Peptide T may also stimulate IL-2 and IL-10 production which would reregulate or down regulate the inflammation and perhaps act protectively in PML, or other neuroinflammatory degenerative diseases.

Peptide T also is believed to have an effect on reducing neuronal cell death or injury mediated by certain cytokines. By both binding CD4 receptor and mediating or down regulating certain cytokines, Peptide T may offer therapy to autoimmune disease where thermostat activation--inactivation balance is distorted and over activation takes precedence.

Treating PML with a drug such as Peptide T offers an innovative approach to an illness with no effective treatment. Even a modest clinical effect would be considered a major milestone.

The use of peptides as herein described are believed to be of most therapeutic benefit as a prophylactic when given early in the degenerative course of the disease to prevent further deterioration.

The peptides used in the therapeutic procedures of this invention are known materials and are described as relatively small or short peptides of up to 30 amino acids having the general formula:

$$R^a\text{-Ser-Thr-Thr-Thr-Asn-Tyr-}R^b \text{ (I)}$$

where R^a represents an amino terminal residue Ala- or D-Ala- and R^b represents a carboxyl terminal residue -Thr or -Thr amide or a derivative thereof, with an additional Cys- residue at one or both of the amino and carboxyl terminals, or a peptide of the formula:

$$R^1\text{--}R^2\text{--}R^3\text{--}R^4\text{--}R^5 \text{ (II)}$$

where R^1 is an amino terminal residue Thr-, Ser-, Asn-, Leu-, Ile-, Arg- or Glu-; R^2 is Thr, Ser or Asp; R^3 is Thr, Ser, Asn, Arg, Gln, Lys or Trp; R^4 is Tyr; and R^5 is a carboxyl terminal amino group or a derivative thereof with a corresponding D-amino acid as the amino terminal residue, and/or a corresponding amide derivative at the carboxyl terminal residue and/or additionally a Cys-residue at one or both of the amino and carboxyl terminals.

Physiologically acceptable salts of these peptides are also included. Also the peptide may have the formula $X\text{-}R^1\text{-}R^2\text{-}R^3 R^4\text{-}R^5\text{-}X$ where R^1 --R^5 are as defined above and X is cysteine.

Preferred peptide are

ala-ser-thr-thr-thr-asn-tyr-thr, thr-thr-asn-tyr-thr,

ser-ser-thy-tyr-arg, asn-thr-ser-tyr-thr,

thr-thr-ser-tyr-thr, ser-ser-thr-tyr-arg,

asn-thr-ser-tyr-gly, ser-thr-asn-tyr-arg,

ser-ser-thr-tyr-arg, ser-ser-arg-tyr-arg,

ser-ser-thr-tyr-arg, thr-thr-ser-tyr-ser, and

cys-thr-thr-asn-tyr-thr-cys.

The peptide is preferably conjugated to a protein, such as human serum albumin.

The preferred peptide is the octapeptide ASTTTNYT also known as Peptide T.

The preparation of these peptides is described in PCT application PCT/US87/01345 published as WO 87/07614 on Dec. 17, 1987 in the names of Pert, Ruff and Farrar, the corresponding U.S. Pat. No. being 5,276,016, the disclosure of which is hereby incorporated by reference to the extent necessary to facilitate the understanding of this invention.

The peptide is administered in therapeutically effective amounts, that is, it is administered in amounts and/or at dosage intervals sufficient to provide therapeutic benefit to the patent. Typically, the amounts administered are generally within the range of about 0.2 mg to 50 mg, preferably 0.2 to 30 mg, per day calculated on the weight of a 70 kg adult human. The peptide may be administered in a single dose or in divided doses and is preferably administered parenterally, usually by injection or infusion, though other administration methods may be used.

One route of administration is intranasal either as a dry (lyophilized) neat powder or as an aqueous solution, preferably a sterile, isotonic solution. The peptide is dissolved in physiologic saline in concentrations of from 0.01 to 50 mg/ml, preferably 1 to 50 mg/ml.

However, aggressive initial treatment may be advisable, depending on the stage of the disease. Continuous intravenous administration by infusion pump, at the rate of 1 mg per hour, for a dose of 24 mg per 24 hours, has been successfully employed with a patient suffering from PML, 8 weeks into the disease. The rate of administration can vary, from 0.2 to 2.0 mg/hr, depending on the course of the disease and results obtained. Levels can likely be moderated once return of function occurs.

The peptides of the invention may be beneficially modified by methods known to enhance passage of molecules across the blood brain barrier.

The compositions usable in accordance with the invention may take the form of suspensions, solutions or emulsions, in oily or aqueous vehicles, and may contain formulatory agents such as suspending, stabilizing and/or dispersing agents.

In one patient suffering from PML, peptide T was administered by intravenous bolus injection of 5 mg. The following day, continuous intravenous administration of 1 mg/hr was undertaken and after 33 days of continuous drug infusion, significant clinical improvement was observed, including subsiding of hemiplegia, neurocognitive improvement and return of motor skills, including the ability to walk unassisted. The progression of PML was apparently halted, and many of the effects reversed.

While preferred embodiments of the present invention have been described, it will be understood by those skilled in the art that various modifications could be made without varying from the scope of the invention.

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Other References

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Something funny amidst the gloom and doom

12:24PM, Friday, 11 Apr, 2008

Amidst all the gloom and doom, one of my friends sent me this rather hilarious piece, which I thought I'd share with you.

Enjoy and remember – LYLO

Pieter

YOU CAN'T FIX STUPID

These people prove it is a terminal condition. As always, competition this year has been keen. The candidates this year are ...

Eighth Place
In Detroit, a 41-year-old man got stuck and drowned in two feet of water after squeezing head first through an 18-inch-wide sewer grate to retrieve his car keys.

Seventh Place
A 49-year-old San Francisco stockbroker, who 'totally zoned when he ran,' accidentally jogged off a 100-foot high cliff on his daily run.

Sixth Place
While at the beach, Daniel Jones, 21, dug an 8 foot hole for protection from the wind and had been sitting in a beach chair at the bottom when it collapsed, burying him beneath 5 feet of sand. People on the beach used their hands and shovels trying to get him out but could not reach him. It took rescue workers using heavy equipment almost an hour to free him. Jones was pronounced dead at a hospital.

Fifth Place
Santiago Alvarado, 24, was killed as he fell through the ceiling of a bicycle shop he was burglarizing. Death was caused when the long flashlight he had placed in his mouth to keep his hands free rammed into the base of his skull as he hit the floor.

Fourth Place

Sylvester Briddell, Jr., 26, was killed as he won a bet with friends who said he would not put a revolver loaded with four bullets into his mouth and pull the trigger.

Third Place

After stepping around a marked police patrol car parked at the front door, a man walked into H&J Leather & Firearms intent on robbing the store. The shop was full of customers and a uniformed officer was standing at the counter. Upon seeing the officer, the would-be robber announced a hold-up, and fired a few wild shots from a target pistol. The officer and a clerk promptly returned fire, and several customers also drew their guns and fired. The robber was pronounced dead at the scene by Paramedics. Crime scene investigators located 47 expended cartridge cases in the shop. The subsequent autopsy revealed 23 gunshot wounds. Ballistics identified rounds from 7 different weapons. No one else was hurt.

HONORABLE MENTION

Paul Stiller, 47, and his wife Bonnie were bored just driving around at 2 a.m. so they lit a quarter stick of dynamite to toss out the window to see what would happen. Apparently they failed to notice the window was closed.

RUNNER UP

Kerry Bingham had been drinking with several friends when one of them said they knew a person who had bungee-jumped from a local bridge in the middle of traffic. The conversation grew more heated and at least 10 men trooped along the walkway of the bridge at 4:30 am. Upon arrival at the midpoint of the bridge they discovered that no one had brought a bungee rope. Bingham, who had continued drinking, volunteered and pointed out that a coil of lineman's cable lay near by. They secured one end around Bingham's leg and tied the other to the bridge. His fall lasted 40 feet before the cable tightened and tore his foot off at the ankle. He miraculously survived his fall into the icy water and was rescued by two nearby fishermen. Bingham's foot was never located.

AND THE WINNER IS ...
Zookeeper Friedrich Riesfeldt (Paderborn, Germany) fed his constipated elephant 22 doses of animal laxative and more than a bushel of berries, figs and prunes before the plugged-up pachyderm finally got relief. Investigators say the ill-fated Friedrich, 46, was attempting to give the ailing elephant an olive oil enema when the relieved beast unloaded. The sheer force of the elephant's unexpected defecation knocked Mr. Riesfeldt to the ground where he struck his head on a rock as the elephant continued to evacuate 200 pounds of dung on top of him. It seems to be just one of those freak accidents that proves ... 'S… happens'.

Notes: Someone sent me this joke which perked me up even further on this day.

Do miracles happen

2:11PM, Friday, 11 Apr, 2008

Hi there

Let's talk about miracles. Let's get positive. Day before yesterday I was down and out. The death sentence hung heavily over Alec's head, and still does. I was in despair. During the night I received an email from Mr and Mrs RTS suggesting I read up on a medicine called XYZ (for now at least). Which I did immediately.

The more I Google this name, the more information I get. And I am not the only one. We are three people devoting our time non-stop, *plus* one biochemical company, researching XYZ. XYZ is an amino acid that, according to a source in the USA who has done more than 20 year's research on this amino acid, is on the verge of becoming a possible vaccine against HIV. It has no toxicity and has the potential to reverse adverse effects created by the virus.

And this is where the miracle comes in – *please please please* pray that we can get this XYZ into South Africa without any problems *and* in time.

And Mr and Mrs RTS – *thank* you for giving me *hope* again.

Now off to hospital to give Alec hope.

LYLO
Pieter

Notes: The more research I did into Peptide T, the more excited I became. I was more and more convinced that we were on the right track. I could not wait to share my excitement with Alec, so Martie and I set off to hospital.

Disaster struck. It was evident that Dad was on his last legs when we arrived. We immediately ordered the nursing staff to get Dad on oxygen. I went outside to have a cigarette and phone my sister to inform her about Dad. She came over immediately.

At some stage I had to go home to lock the house and to pay the gardener, and then I returned to the hospital. I remember phoning our minister, who came out to hospital. He did Dad's last rites for him. The nursing staff did not send us home but did suggest that we go home at about 22:00 to get some rest.

Whilst Martie and Joey remained beside Dad's bed constantly, I had to divide my time between Dad and Alec. Alec was looking well and would not let go of my hand. I kept on telling Alec about this miracle drug that we were importing for him.

Dad

11:07PM, Friday, 11 Apr, 2008

Hi there

Short post – Dad seems to have taken a turn for the worst. We have just returned from hospital after they convinced us that there is nothing more that we can do but come home and have a rest. They will let us know if things get worse for Dad.

Alec, on the other hand, is looking rather good at the moment. He recognised me again today and would not let go of my hand.

But, in my heart of hearts, I have said goodbye to Dad tonight.

LYLO
Pieter

Roller coaster ride, roller coaster

Notes: We tried to sleep, but did not really sleep. Joey was very concerned about my emotional well-being and requested that the hospital rather phone her should something happen to Dad. The call came shortly after 12:00.

RIP – Lourens Daniel S

1:46AM, Saturday, 12 Apr, 2008

Just a short note to let you know that Dad has passed away shortly after 12:00 this morning.

LYLO
Pieter

Notes: I remember Joey coming into my room, waking me gently and telling me that Dad had passed away. It did not sink in. I suggested we try and sleep a bit and then deal with it later in the morning. But as I put my head on the pillow, it struck me – Dad was dead!!

Joey and I got up. We did most of the planning of Dad's funeral in the early hours of that morning whilst we waited for the sun to rise before we could start phoning family and friends. I remember not looking forward to going to the hospital to claim Dad's body. But at 09:00 Joey and I went to hospital to go and fetch Dad's belongings. I burst into tears as we entered the ward and saw Dad's belongings neatly packed in the nursing staff's office. They told us that we could only claim Dad's body on Monday as the relevant personnel were not on duty. We went back home.

I phoned the undertaker and booked Dad's funeral for the Friday. By this time everybody had been informed of Dad's passing.
Annemarie and Simmi came to visit and pay their respects, and also to come and visit Alec. All of us agreed that it would be in Alec's best interest if he did not know that Dad had passed away. We decided to tell Alec that Dad had been discharged, because we were afraid that if he were to find out that Dad has passed away, it could upset him and expedite his deterioration.

A Tribute to my Dad

2:01PM, Saturday, 12 Apr, 2008

Born on the 22nd of May, 1933, Dad was the first of 5 children. Grew up on a farm in the Ventersdorp district in the depression years. At the age of 10 he contracted polio, there were no vaccines then, and lost the use of his right arm. He was teased at school because of this and in later years, when he started dating, one of his date's father said that he does not have a problem with Dad's friendship with his daughter, *but* that he does have a problem with a relationship (long term) because they don't want crippled children (because of my Dad's arm).

In later years this would make my Dad a fiercely protective and proud man, not reliant on anybody for anything. He was the provider of the house, the patriarch, and that he remained till he passed away.

Dad met Mom somewhere in the 50's and got married in '57. They were devoted to each other. From their marriage we were 3 children, Boeta (who passed away in '79), Sussa and me. As a father of young children Dad was very strict, and we did find him distant with us. But as we became adults, Dad became a different man. A man who I was proud to call my best friend. A man who did not reject me when I told him I was gay. A man that lived and thrived on his children's accomplishments. A man who never had a bad word to say to or about anybody. A man I called Dad or Daddio as terms of endearment.

In his later years, Dad became a proud gardener. The farmer instinct in him could never die, and he was very proud of his vegetable garden. And it made him happy to share the surplus from his garden with those in need or friends.

He loved his little trips and going on the plane. In fact the photo above is of him at OR Tambo last year March on our way to Ramsgate.

I feel sad about my loss, the void is huge. But I know I loved him. In fact I told him so everyday. And I was not shy to say it either. And last night, before we went home, I told him that again. But I also said goodbye. And he squeezed my hand.

Pappatjie, rest in peace. We shall miss you. And our memories of you will never die!

Feedback re Alec

I visited Alec this afternoon along with Anne and Simmi. I told him that Dad is discharged from hospital and recovering at home now. I will rather deal with lying to Alec when he recovers than causing a shock reaction because of Dad's passing that could endanger Alec. I know, that should Alec recover, Dad's passing will have a huge effect on him, because Dad was a Dad to him too.

Also, thanks for the messages and respects on Dad’s passing. Dad’s funeral is scheduled for Friday morning 11:00. I will finalise the arrangements with the funeral parlour on Monday.

Notes: I remember that on that Saturday afternoon, after Annemarie and Simmi had left, I broke down for the first time about Dad’s passing.

I also remember visiting Alec that afternoon was extremely difficult for me. As I walked into the ward my eyes immediately fixed on the bed Dad had lain in. Right opposite the isolation ward Alec was in.

Sunday morning

8:35AM, Sunday, 13 Apr, 2008

Morning all

Again thank you for your kind comments, posts and wishes of condolences to our loss of Pappatjie. Aunty M, Sussa and myself appreciate it immensely.

Most of Dad's funeral is planned already, the time and date is set, all I have to still do now is claim Dad's body from the mortuary, which can only be done tomorrow, get his death certificate and hand all this to the funeral parlour. Sussa designed Dad's funeral letter and Dad would have been proud of it. Although they were not married, we do recognise Aunty M as Dad's life partner and we have involved her as far as possible. I think the realisation of it all struck me yesterday afternoon and I was finally able to cry over Dad's death.

From where my house is, I can hear the highway. And the highway reminds me constantly that life goes on. It does not stand still. Nothing I can do will ever bring Daddio back. But Alec is still alive and therefore all my energies must now be focussed on him.

I phoned the hospital this morning and they told me that Alec is trying to lift his feet, which is a good sign. He will be spoilt rotten today when he gets visited by no less that 4 fellow bloggers!!!! I am sure that that will lift his spirits a lot.

So, without any further ado, let me go and have a shower and get things ready for when all my people arrive.

Take care all and remember, please, and from the bottom of your hearts:

LYLO

Pieter

Notes: This was the day Heidi arrived from East London. A fellow blogger who writes under the name Blanket offered to meet Heidi at the bus stop in Midrand and then bring her through to Stilfontein. They arrived at about 09:30 that morning. Shortly afterwards RTS and Ramona arrived to offer their condolences and to visit Alec. We all set off to hospital. Heidi, Blanket and Blanket's daughter in Blanket's car and RTS, Ramona and I in their car.

I remember Ramona being very upset upon seeing how Alec had deteriorated since the 19th of March when they had last seen him. Blanket was also visibly upset. But we all agreed that we would remain positive and gave Alec reassurances that the medicine was nearly on its way from America. Little did we know it would be Alec's first and last visit with Blanket and Alec's last visit with Ramona and RTS – two people who would have gone to the end of the earth to help and assist the two of us.

Upon our return home I made a quick and easy lunch consisting of bread rolls and cold meats and other fillings. Joey joined us for lunch as she had been looking forward to meeting RTS and Ramona. After lunch RTS, Ramona and Blanket left.

Tuesday morning

7:10AM, Tuesday, 15 Apr, 2008

31 December 2007

What a glorious day. Anne came over, Sussa was here, Alec, me, Dad, Aunty M. We decided to have a little ritual – one of each collecting a rock or stone of some sorts, naming it one of the things that bothered us the most in the year that and burying that problem.

Little did I know that 2008 would be one of my most testing years!!!! My *annus horribilis.*

Yesterday we went to the hospital to see if we were needed for anything there. All they did was to give us the notification of my father's death and said we could take it to any undertaker who would then issue us with a death certificate. We went to AVBOB and this is where things started getting difficult. Not financial or technical, no, but emotional. All of a sudden you are confronted with a myriad of things – I think the most important one was that of choosing a casket. It sounds so easy – a casket is a casket. But what do you do if you are confronted with 20 caskets to choose from (and bizarre as it may sound – you fear there is a body in it?)

Very long (and emotional) story short – Dad's arrangements are finalized. All we still have to do is to go and view him late Thursday afternoon (apparently we have to make sure that it is Dad in the casket – bizarre), and then on Friday morning the funeral will take place. And I dare say that it will be a funeral Dad would have been proud of. Fitting of his character, subdued without being skimpy, well planned. Thank you Sussa for assisting me.

We went to see Alec at 15:00. He was *not* looking good. But I stroked his cheek and begged him to hang in there for us. As we left the hospital we saw the van from the undertaker parked next to our car – they came to collect Dad's body and we were out of there like a bat out of hell. We did not want to see it.

Alec's condition was pretty much the same during our visit of last night, though we did manage to feed him a whopping 45ml of home made soup a'la Heidi. He did recognize me and respond to a foot tickle.

There are several people working around the clock and non stop to get us the medication for Alec. I *really* do not know what I would have done without them. Really, I don't.

I also don't know what I would have done without Heidi!! She is a star. I feel as if I have reached the end of my emotional strength and find it harder and harder to remain calm. I have just lost Dad, and it feels as if I do not have the time to grieve about him. And when I do, I feel guilty because then it feels as if I am neglecting Alec. And in between there is the sorting of Dad's stuff – for emotional reasons I do not want to leave it for too long. And though I do have Dad's death certificate, it still feels unreal and I still cannot come to terms with his passing. And let truth be told – I am scared I will loose Alec too.

I am seeing my therapist at 11:00 today. I look forward to it – actually. I need to dump. Big time.

Special notice:

Many thanks to those who stand by me, offering their time, help and financial assistance in helping Alec unconditionally and unselfishly. I really *do* appreciate it, even though it does not look like it at the moment. I am just worn. But I really *do* appreciate your help.

And a special word of thanks to you as well, for your comments, emails and phone calls of support. Understandably I do not have the time to thank each one of you personally, but the time will come that I do. I promise.

LYLO
Pieter

Notes: I was too exhausted to blog on the 14th. There were so many arrangements to be made. I remember that I was very overwhelmed when it came to choosing Dad's casket.

On this day I thought back on our get together ceremony on 31 December 2007. Last Old year together. Last New Year together.

I remember at the time, when the phone rang late at night or early in the morning, I feared it was the hospital. And it was no exception that on this night when the phone rang well after 20:00. Luckily it was Trevor in Utah, USA – just to inform me that the parcels of Peptide T had been dispatched to him, and that as soon as he received them, he would send them on to me. I remember being so relieved that I laughed and cried at the same time. I remember thinking "there's light at the end of the tunnel."

Wednesday morning

7:30AM, Wednesday, 16 Apr, 2008

Life goes on

Although it feels as if it came to a standstill.

Decided that because we are in an emotional turmoil already, now would be a good time to sort Dad's stuff and keep what we want to keep, give away what we want to give away and turf what we want to turf. No need to wait for the pain to heal and then starting the whole process from scratch again. So yesterday saw us sorting through an Everest of stuff. Inspecting, introspecting, digesting and poring over each and every single scrap of paper. Well, we have just touched the tip of the proverbial iceberg, but I am set for us to finish asap.

Saw my therapist yesterday. She again recommended anti-depressants but in the end conceded that I am coping well given my circumstances.

Alec looked better yesterday, I dare say, but people who have not seen him, would not understand what I mean by better. Better does not mean sitting up in bed and chatting. Better means that he reacted to touch on his left foot, or that his breathing is less haggard. He is still very critical, and signs of 'betterness' are measured in 0.1%'s, not 10%'s.

Had the honour of speaking to our buyers in the US of A last night, and I am amazed and humbled by the extent people are putting themselves out to *help* Alec. Our friends in Utah (though we have not met in real life yet) – *thank you*. If all goes according to plan, we can expect the first delivery Sunday or Monday. *Pleeeezzzzz* keep your fingers crossed.

Heidi is settling in nicely and it is such a relief having her here and taking so much of my shoulders.

As always – *thank* you to our benefactors. *Thank* you to Heidi, *thank* you to you who keep us in your prayers and thoughts.

LYLO
Pieter

Notes: In order to keep my mind off Alec and the medicine that we were waiting for, and also off my dad's passing, and in anticipation of all the family that were going to arrive, I did a good spring cleaning on this day. I steam cleaned the carpets and Heidi and our domestic dusted everything off and washed the windows.

Thursday morning

7:11AM, Thursday, 17 Apr, 2008

So. Yesterday was spring cleaning day – in the middle of autumn. Steam-cleaned the carpets, washed the windows, have to admit that Heidi and Aunty M are both task mistresses, and I don't complain, it keeps my mind occupied and out of mischief (the deep dark recesses of doubt, too much introspection and more than enough "what if" scenarios). Must just do something about the heart stopping every time the phone rings.

One day I will post about the hypocrisy of death. At the moment it angers me too much.

Good news though – Alec has been much more responsive yesterday than any other day so far since his re-admission to hospital. Excellent news. Though PML, I have discovered, is very cyclic in nature, it was very encouraging to see Alec so responsive yesterday and it gives me sufficient hope to see him through till the first batch of meds arrive. I am convinced that we will see a huge improvement once Alec receives his first batch of XYZ.

And then last night Heidi and I started on my business formally. I am sure she will come right.

Today there is just *one* unsavoury thing that needs to be done. We have to view Dad's body at 16:30 in order to verify that it is indeed his body in his casket. And then tomorrow is the funeral, though there will be sort of a wake for Dad, the funeral will finish early enough for a group of us to visit Alec in Hospital and me to escape said wake. Heidi, me, Anne, two other bloggers, a friend of mine from Witbank. We will go and brighten Alec's day. Remind me to blog about the hypocrisy of death sometime.

Once again – I really do appreciate all your comments and your support, your thoughts, your emails. It really helps a lot in this very trying time.

And remember – LYLO!

Love
Pieter

Notes: A long standing friend of mine, Pieter du Toit came around in the afternoon, and asked me to accompany him to Klerksdorp. He had some errands to run in preparation of a platter and to purchase flowers for the church, which I had ordered from them for Dad's funeral. Pieter and his family have a Catering Company.

Whilst in Klerksdorp we stopped off at a flower wholesaler to select the flowers Pieter wanted to use in the church. Pieter showed me that day the biblical verse: “don’t let your right hand know what the left hand is doing” in action.

I recall on our way back to Stilfontein, I burst out in tears, because I remembered a little lecture from my dad. Some two years before Pieter did something that made me very upset – he withdrew from a project that we were working on together, without giving any reasons. I decided to break all connections with him and his family. Dad was unsettled by it, and said to me that I must never throw the Du Toit’s away – that they were good people.

After I met Alec, we had bumped into Pieter in the Spar one day and had slowly rekindled our friendship. During Alec’s illness Pieter became more and more involved and supportive. And on this day Pieter bought the flowers out of his own pocket for Dad’s funeral. He would not accept any money I offered. Thus proving my Dad right, even in his death.

I remember the viewing of Dad’s body to be extremely emotional. We had to be at the undertakers at 16:30. Initially Martie indicated that she would not go along, but when the time came to leave for the funeral parlour she said that she wanted to go along after all. They had laid Dad out perfectly, but I remember when I kissed him goodbye he was so cold.

It was then that the final reality set in – he was dead. And that was the last time I would see Dad.

Dad's funeral, the hypocrisy of death and Alec

7:24AM, Saturday, 19 Apr, 2008

So. We have sent Dad off with what I would like to call a worthy ceremony. It started with Josh Groban’s “You Raise Me Up” as we walked into church, then Dad’s favourite Scripture, Ecclesiastics 3, one song that we sang and then ended with another gospel song in Afrikaans. Sussa and I decided that singing at a funeral just does not work.

The feedback we got from funeral goers was that it was different yet refreshing and so typical of Dad. We are happy if they saw that was what we had planned for Dad and I am sure that he was smiling down from heaven on us.

Dad's viewing was very emotional for me on the one side, yet strangely calming as well. They really made an effort to make him look well and I really have to commend the undertaker.

But it finally brings me to the hypocrisy of death. I hate funerals with a passion. Invariably you'll find that the lowliest form of life becomes the most beautiful person ever to roam the face of the earth. Not that this applies to Dad, no, but it is a fact that no bad words are ever spoken about a dead person. One would expect adversaries to do quite the opposite of what they are doing. That is the one hypocrisy. The other is the people who now start blaming themselves, as in Dad's case, for not making the effort to see him. I got blamed by my one uncle for not having Dad on display. He wanted to see Dad in his coffin one last time. My question is where this same said uncle of mine was when Dad was still alive. Our doors were always open to him and his family. In fact, to any of those who cried the longest most sorrowful tears about Dad. Where were they when Dad was still alive? Why cry now, when they actually could have smiled on the life and the times of a beloved that has now passed away? And then they have the audacity to say we must not wait until the next funeral before we see each other again. Words I remember hearing in 1987 and 1988 when grandma and mom passed away. Then they ask if we have something they could remember him by – and my reply? Yes, sure, you may keep the funeral letter.

I also think of long standing friends of my family – they were like a second mom and Dad to me. All these years I admired and respected them. 10 years ago they moved away to a big city. ALL that time we maintained contact. And when someone passed away Dad made an effort letting them know. And they would attend the funeral. Now that Dad passed away I got this lame baked excuse of why they can not make it. It just illustrated to me that all these years we were nothing but pawns, subjects to them. Nothing else. And therefore they are not worthy of being on my telephone list anymore. I'd rather focus my energies on those strangers that stood by me through thick and thin.

Then you get the self appointed mourners. People that feel compelled to share your sorrow with complete and utter strangers. And then they think they help you in the process. Last week Saturday I phoned P&M at about 05:45 with the news of Dad's death. They were at my house at 06:00. Then Sussa and I needed to go to hospital to get Dad's stuff and asked them to sit with Aunty M as we were concerned about her and did not want to leave her alone. They came back at 08:00 and gave me a list of no less than 10 people who passed on their condolences about Dad's passing. I do not know *any* of the 10. Same said person starting taking photographs of all the family attending the funeral on her cell phone, as if it was a wedding reception. I lost my cool and asked her to stop taking photographs, that I don't want any photos. Her reply? "But I want photos"!! What on earth for? She is not even family.

Enough! May Dad rest peacefully. It is ironic – Dad in his later years always enjoyed sitting somewhere in the shade of a tree. When we laid him to rest, a huge karee-tree cast its shade over Dad's grave. And to me that was so fitting. So as if God was saying "Rest in peace my child".

Alec. Night before last Alec had tremendous difficulty breathing, so I ordered he go on oxygen. Immediately his breathing improved. Yesterday he looked better again, but was still on oxygen. Heidi, bless her soul, thought it wise to leave Alec and me alone last night, and Alec immediately relaxed before he fell asleep whilst I was stroking his hair. All he wanted was some alone time with me. And that was so special to me. I am now more optimistic than ever that things will work out with this meds, which we expect any day soon now.

But – when I say Alec is better, it does not mean he is sitting up in bed chatting away a storm. I measure better or worse in his eyes, how his eyes look. Whether he recognizes me or not. Whether his eyes follow me around the room or not. Whether his breathing is normal or haggard. Whether he responds to a tickle of the right foot or not. Whether he takes 10ml of soup or not. Whether he can move his head from left to right and back out of his own accord. Positive reaction to these indicates whether he is better or not.

So my friends – today I look forward to a peaceful and quiet day void of hypocrites with just my family with me. Sussa, Aunty M, Heidi, the two daughters. Would not have minded if Anne and Simmi were here too. But the family? They are all gone now and I sigh a sigh of relief now, being rid of them.

Take care of and *love* your loved ones. LYLO. And you know why.

Love
Pieter

Notes: I recall that Joey came over on the Thursday night to spend the night with us. She and I shared my bed. Sometime during the night I heard the door open and saw the figure of a woman peeking around the door, and looking into the room. Joey saw her too. At the time I thought that perhaps it was Heidi who was wandering in her sleep.

The next morning I asked Heidi if she got lost in her sleep. She looked at me perplexed and I explained to her what we had seen. She assured me it was not her, so I asked Martie if she perhaps had peeked in to check on us during the night. And she also assured me it was not her. Joey and I have to concur that perhaps it was our late mom who came to check in on us.

Something that particularly annoyed me was people lamenting because Dad was dead. I had informed each and every one of them myself of Dad's illness. For all of Dad's living years his doors always stood open for his family to come and visit him. Dad was always the one that phoned his family, they rarely phoned him. And now they were all crying because he was dead, and saying stuff like what they would give to see him one more time. It was for this reason that Joey and I decided that after the casket was closed on the Thursday, no-one else would see him.

After explaining to the family that there would be no viewing, one of my cousins came up to me and asked if there is really no way that they could view Dad's body. So I said no, the casket was already sealed tight. I mean this coming from a cousin that did not even bother to contact Dad in over 20 years?

I remember distinctly that I was not looking forward to seeing the family that morning. As it was, they started arriving early. Heidi was a star keeping the coffee flowing. I went to church early to sort matters out with the verger.

Another moment I also remember distinctly, after carrying Dad's casket to the hearse, I had to go to my car. On my way to the car, Pieter du Toit's mom walked towards me, opened her arms and just held me. And all I could do was cry and cry.

After Dad's burial a few of us went through to the hospital to visit with Alec. I remember changing from my church clothes into more informal clothes so that what I wore would not give away to Alec that I had attended a funeral.

Sunday morning

9:51AM, Sunday, 20 Apr, 2008

Alec looked very much better yesterday. When we arrived at the hospital, he was off his drip and off the oxygen. *Okay*, the drip was only a temporary thing, they explained (it was back on last night again), but the oxygen was not needed anymore as he has recovered from his sinus problem he had that caused his need for oxygen. Also, Alec was much more responsive to us and much more alert.

And I am afraid that is the only feedback I can give about Alec, for now.

The house seems unearthly quiet without Dad. I had a few emotional moments yesterday, which saw me bursting out in tears. I tried to alleviate that by doing something constructive and positive such as watering the garden, etc. Aunty M's son came to visit, and I had the hunch that it was only to establish what was going to happen to his mother. So I went through the clauses of dad's will and said to him that Aunty M has the right and the choice to stay on as long as she wants, and that I will not act against my father's explicit wishes and a promise I made him in January already, that should he go before she does, I will continue to look after her with the same loving care I would look after him. I dare say that Aunty M's son and daughter in law both looked very relieved.

Revisiting the hypocrisy of death – last night I stopped off at the garage to fill the car and buy myself some airwaves. A lady (known in Quiet Fountain as a lady of the night) that knew, but despised, my dad, works in the shop. As I walked in she asked: How's your dad? (No secret I despise her) I answered: I buried him yesterday. Upon which she wailed inconsolably and uncontrollably, to such an extent that I wondered if I should not get a doctor in to treat her for shock. Then the questions started, why did I not tell her, when did he pass away, etc. I made short of it by just replying that because Dad knew so many people it was an almost impossibility to let everyone know he passed away. On our way to hospital I told Heidi that she should mark my words – this story is now going to spread like wildfire. See, said lady is associated with some people my Dad gave shelter to some time ago. They robbed us blind and some time ago, could be September or October, I blogged about this woman and her daughter who had a crush on me and how Aunty Fag Hag and I "got engaged" just to get rid of the attention. Well, this morning Aunty M told me that they phoned from East London about 19:25 to sympathise. I told this other girl at about 19:15 that Dad has passed away.

Well, that is me this morning. Grab yourselves a wonderful Sunday. Catch you all tomorrow again.

And as always – LYLO

Love
Pieter

Notes: It was rather hilarious, the way this girl reacted.

I remember how concerned I was with Alec's breathing. His cheeks were billowing like a race horse's cheeks. It was really frightening. At this stage though, I had a very good relationship with the nursing staff and my wish was pretty much their command. They immediately put Alec onto oxygen and this seemed to calm him down somewhat.

Magic Monday

7:27AM, Monday, 21 Apr, 2008

Another Monday. Another day. Seeing the therapist today again, and I suspect she will be happy that I feel better.

4th day in a row that Alec was looking better. He even tried talking to me yesterday. Okay what came out was only mumbling sounds, but I know he tried to talk to me. He lifted his head up, looked me in the eye and started this mumbling sound. Hallelujah.
I also started preparing Alec for the news of Dad's passing on. All positive, don't worry, I just told him that he has a special angel looking over him. And that is where I am going to leave it at.

Sussa had a difficult day yesterday. I think the realisation sunk in on her that Dad is there no more. Had a good crying session with her on the phone yesterday afternoon. I also did something very difficult yesterday – having a braai. I felt so guilty. Alec lives for his braais and Dad also enjoyed his braai. So something as insignificant as a braai yesterday afternoon became an emotional healing process.

Life has the nasty habit of going on. As much as we want it to stop, even just for a while, you find that if you do not continue you will be left behind. So instead of moping around, I will spend today with the firm belief in me that Alec *will* get better. I will keep on believing that with every nerve, cell, fibre and atom in my body. I will keep on believing that Alec will come home soon. I will keep on believing that he will wake up from this *very* nasty nightmare, that we will reflect back on this, and smile. Smile with the knowledge that we love each other, but more importantly, that God loves us!

May your Monday also be magic.

And remember: LYLO!

Love
Pieter

Notes: In anticipation of receiving the medicines, I requested from the doctor that a CD4 count be carried out on Alec's blood. For me, proof that the Peptide T was working, would be that Alec's CD4 count would go up once the Peptide T was in his system. And in order to establish that I needed to have his latest CD4 count.

I am a winter woozy

7:25AM, Tuesday, 22 Apr, 2008

Winter has descended upon us with all its fury!! *Brrrrrrrr!!*. Along with Kerneelsie some time in August/September last year we promised *not* to complain about the heat. Well, we didn't. But sure as hell I *will* complain about the cold. See, I do not handle winter well.

Me thinks my new addiction has arrived! Answerit! Such fun …

Yesterday was a very positive day for me. Heidi and I spent some time on the business, got her sorted out in office and email set up, she even did a very brave attempt at a quote!

Then I was off to see my therapist – she is of the opinion that she does not have to see me again, unless I feel like it. Happy with my progress and she said that it is first class that I opted against anti-depressants. Then I spent some time with Alec, who was looking very much the same as the previous day. No positive reactions though, but then, nothing negative either. Last night the closest I got to something positive was him holding my hand.

The meds should arrive any day soon now – so I am waiting with bated breath.
Yesterday afternoon I got rid of a wire fence that has been bothering me for quite some time now. Must admit the physical work did wonders and of course Heids has been a great help too! It will however take me some time to get used to the new space that was created. Today I want to tackle the garage, but I suspect there will be enough work there to keep me busy for years to come. With Answerit, I think I should rephrase – decades ...

And that, dear friends, is me for the day.

Take care, and remember, LYLO!!!

Love
Pieter

Notes: I remember that I continued to keep myself busy with all sorts of things to keep my mind off anxieties I had about Alec.

Heidi needed to learn the ropes of my business and I remember us having regular lessons on the destinations that my company represented. It also kept my mind off wondering if and when the Peptide T would arrive.

Later, that afternoon, I went to Spar and saw there the most beautiful bouquet of carnations. It was an unusual bouquet, as it contained four or five red ones and a single white carnation and some greenery. All the other bouquets of carnations were a riot of colours. The red carnations were so intensely coloured, that they looked nearly black. I did not buy them immediately, but en route to the hospital for our evening visit, I decided to go and buy them, so Heidi and I went to Spar. I remember that I was quite anxious – afraid that this particular bouquet had already been sold. Fortunately it was still there.

I am convinced that Alec was happy to receive those carnations – I could see in his eyes he appreciated them. That was the last bouquet of flowers I bought Alec in his life.

And life continues

11:34AM, Wednesday, 23 Apr, 2008

So, where were you, you ask. Me, myself and I and Heidi kept ourselves out of mischief this morning with loads and loads and loads of quotes. Happy to say that *thankfully* Heidi is a very fast learner, and if things continue as they are, I will be able to leave her to her own devices one of these days. It does help that we get along really well.

Alec? He is still hanging there. I thoroughly enjoyed our visit last night and he thoroughly enjoyed the attention he got. I just wish the damn medicine will arrive now. I am like a boy with a new toy with it and can't wait to see if it will help Alec.

Apart from that, I am afraid, nothing else to report.

Have a wicked Wednesday and do *not* spend too much time on Answerit. Such fun!!!

You take care

LYLO
Pieter

Notes: I remember almost pacing the house impatiently as I waited for news regarding the Peptide T. Heidi's brother Matt had purchased 30 milligrams and Trevor and Rene had purchased another 30 milligrams. Trevor and Rene were planning to split their purchase and then dispatch it to three different addresses I had supplied them with, one being my home address and the other two to friends of mine. This was to ensure that at least one of the batches would arrive, should there be a problem with customs.

Matt on the other hand was planning to courier the batch he had purchased to South Africa and I was anxiously waiting to hear that it was on its way. I believed firmly that the sooner it could get here and the sooner I could get it into Alec's body, the sooner he would start to get better. I was fighting this thing tooth and nail

Heidi had taken to massaging Alec's hands and feet with some Oh So Heavenly cream every night. I would stand at his head and run my fingers through his hair, which by now was very long. And whilst we pampered him, he made these mewling sounds, which we interpreted as enjoyment. And as I moved from one side of Alec's bed to the other, Alec would move his head and his eyes would track my movements. We were very much encouraged by it.

I also did the test Dr Luke had performed on Alec every day, by tickling his feet to see if there was reaction. Some days he would pull both his feet away, other days only his left foot. I did this test as soon as we arrived. Then I would read his file to see what Dr Griffith's had observed.

On this night, I remember that Alec was not looking well, and I requested that the staff put him back onto oxygen, as his breathing was haggard.

I remember the feelings of conflict: anxiously waiting for the Peptide T because it would help him, fear because I felt I was about to lose Alec, but then also a feeling of it was not fair to see Alec suffer this much. And though I firmly believed that the Peptide T would help, I remember shooting up a prayer to God saying that HIS will should be done. I was not giving up on Alec, but at the same time I could not bear to see him suffering.

Wednesday morning

10:21AM, Thursday, 24 Apr, 2008

Hi there, Blog friends

Alec was not well last night and a phone call to the hospital this morning revealed that nothing has changed. I have put him back on oxygen last night.

Please pray that Alec will recover asap.

LYLO

Pieter

Notes: I note now whilst I am writing these notes, that I had called the post Wednesday Morning, when it should in fact have been Thursday Morning. I was despondent and depressed and anxious. Each time the phone rang, I had an anxiety attack because I feared it would be the hospital with the worst possible news.

Matt had contacted us early in the evening – he was at his local courier office and had been having difficulties in dispatching the Peptide T, as this particular courier company was unable to send a package via express mail to Stilfontein, and they also required an invoice to verify the contents of the package. As they had had to disguise what was in the package, he did not have an invoice, so he was waiting for his partner, Jay to meet him there and they would be going to the next town with a different courier company who did not require all this documentation and were planning to dispatch the disguised medication post haste. By this stage everyone's nerves were frazzled especially mine, because it was so frustrating knowing that these people had the medication and that they were having difficulties in sending it through. I remember telling Heidi that if I could I would catch the next flight to the USA and fetch the medicine myself and smuggle it in through customs – but that was an impossibility

Soon after this very frustrating phone call, Heidi and I went to visit Alec. As we walked into his room we knew it would not be long anymore. His breathing was extremely laboured – his cheeks sucking in when he inhaled and billowing out when he exhaled. He did not respond to my touch.

I recall reading from the Bible, our passage, 1 Corinthians 13, as I did every night. It was the most difficult thing for me to do and I choked on my tears very often. Sometimes my eyes were so full of tears that I could not make out the letters in the Bible. I remember that my lips were trembling.

I remember telling Alec he must not be afraid – that he had a special guardian angel standing next to him, guarding him and protecting him. Here I referred to Dad, the man Alec so admired. As she usually did, after spending some time with Alec and mainly stroking his hair, and talking to him, Heidi said goodbye to Alec and left us alone together.

I remember saying goodbye to Alec for the last time. I kissed his forehead and then I kissed him on his lips. I told him I loved him. One last time. I gave his hand a squeeze. He squeezed mine back. Perhaps it was reflex, I don't know. But I like to believe it was not.

I realised I would not see Alec alive again, and left instructions with the nursing staff to phone me the minute things deteriorated. They agreed to phone me.

On our way back to the car, an owl hooted. Thrice. For the second night in a row. I remember a shiver going down my spine. But I am not a superstitious person and tried to shrug the feeling of dread away.

Alec Willem de Lange 21 June 1970–25 April 2008

5:17AM, Friday, 25 Apr, 20085:17AM, Friday, 25 Apr, 2008

Alec passed away at 04:00 this morning. My second loss in as many weeks.
Thank you for the short time you have enriched my life – darling. May your soul find rest from this cruel, brutal world.
I will miss you
Love, eternally
Lylo
Pieter
I really love you Alec. I really do.

Notes: The call came at 04:30 am. Strange how one knows when a call is not a friendly one. Strange how you know it is not a friend phoning you to find out how you are. Strange how you know what the caller is going to say: "we are so sorry Mister Stols. Alec has just passed away".

Heidi had heard the phone ringing, and had risen – as I walked down the passage towards her room I saw her standing in her doorway. I managed to choke out "It's over" and she walked down the passage towards me and we both hugged each other and cried.

I woke Martie up. She started to cry. I could not wait till a decent hour to let Annemarie know. She answered her phone with a trembling "Pieter?" And then I did this post.

During the night an email came from Matt in the USA to say he would be dispatching the medication shortly and apologising for his being as he put it a "bit snippety on the phone". I cannot remember who wrote the reply because it is unsigned, but I think I did. The events of that morning are a bit of a blur.

Heidi posted the following post a little bit later (post used with the kind permission of Heidi Lindner).

http://mynewsblogs.24.com/ViewComments.aspx?blogid=86f7dbbf-0eef-4f29-a930-b559df565900&mid=66543bde-90bd-4106-833b-ae1df443b119

Carnations for Alec

7:35PM, Friday, 25 Apr, 2008

A few days ago, Pieter and I were in the Spar, where a beautiful bouquet of the deepest red carnations and one pure white carnation caught his eye. That evening before we set off to visit Alec in hospital, we returned to the Spar, and Pieter bought the bouquet and took it to him.

According to Christian legend, carnations first appeared on Earth as Jesus carried the Cross. It was then that the Mary shed tears at Jesus' plight, and carnations grew from where her tears fell.

Dark red carnations denote deep love and affection, while white carnations indicate pure love.

The bouquet that Pieter placed at Alec's bedside was a symbol of their love for each other, and even though Alec could no longer tell Pieter that he loved him with words, it was clear in his eyes and in the way he would become calmer at the touch of Pieter's hand.

I have been privileged to experience first hand the love that these two people shared, and I stand in awe.

To everyone who has left messages of support on Pieter's blog. To the person who created and to all of those who have left messages on the In Memory Blog. To everyone who has phoned, smsed, emailed. All I can say is "Thank You". Your support has been overwhelming.

Aan Alec: Ek wens ek het die kans gekry om jou beter te leer ken. Jy en Pieter was en is 'n insperasie vir my. Ek weet jy is nou op 'n plek waar daar nie meer pyn is nie, waar jy nie meer sukkel om asem te haal nie, waar jy nie meer verward is nie, en dit is 'n groot troos. Ons gaan jou mis, liewe Daddy A.

Rus in Vrede.

Translated: To Alec: I wish I had the chance to get to know you better. You and Pieter were and are an inspiration to me. I know you are now in a place where there is no more pain, where you don't struggle to breathe, where you are no longer confused and that is a great comfort. We will miss you dear Daddy A. Rest in peace

Notes: The "In Memory" blog that Heidi refers to was created by a dear blog friend who wrote under the name Hutton. She called it a memory kit.

Annemarie came through early that morning. She was at my house by 09:00. I selected some clothes for Alec to be cremated in – his favourite pair of black pants (in which he had looked so good 2 months ago), his favourite white shirt, his favourite underpants.

We then set off to the hospital to collect Alec’s belongings. I remember leaving the carnations there, I could not face them. The head nurse took me in her arms and cried with me. I found it so compelling, especially so coming from an African lady.

We then went to a funeral parlour managed by a friend of mine to arrange Alec’s cremation. The date was set for 29 April – 12:00. I remember Dawie, the undertaker and also my friend asking me: “Are you okay?” I shook my head and broke down. He organised for Annemarie and I to receive grief counselling on the morning of Alec’s memorial service. That same morning we would go to view his body and say our final farewells.

Epilogue

My Darling Alec
5:28AM, Tuesday, 29 Apr, 2008

Today I am doing the most difficult thing I have ever faced in my life. I'm sending you off.

There are so many things that we still wanted to do, so many things that were in the planning stages. We were to be married on the 15th of March, remember? Only a small reception – nothing fancy.

Remember the day we met – the 18th of June 2007? Venus's occultation with the moon. Deep inside our hearts we got married that night – the 15th would have been only a formalisation of that.

Remember the Vic Falls? The bungee, the helicopter flip?

Remember our rose garden? How you would pick me a rose, every day you had a chance you picked me one. I always had a rose next to my bed. Pink, yellow, red or white. In the mornings, because I wake up early, I always made you your first cup. At 06:00. Then we would watch telly until 06:30 until you had to go and take your shower. By 07:00 your next cuppa would be ready. At 17:00 when you got back from home we would have a sundowner before having supper. You'd help me with the finishing touches. Over weekends we would cook together. I remember how agitated you would get if I dared light the fire for a braai if you were not here yet. Now I am not sure that I'll be able to face a braai again.

I remember our Christmas tree, the lights, the tinsel. Your first Christmas tree, you said. I am not sure I will be able to take that tree out again, it will hurt too much Alec.

Darling, I want you to know, please. I have loved you. I still love you. I will always love you. I am not angry with you for leaving me alone. I am hurt, but not by you. I am hurt because I am alone again. I am hurt because there is nothing more I can do. I am hurt because there is nothing else I can do but cry. When you were ill, and still breathing, I knew we had a chance. Now there is no chance left. And it makes me feel helpless Alec.

Thanks Alec, for all we had. Thanks for being the ONE person that brought sanity in my life. Thanks for being the ONE person I trusted with every single fibre in my body. Thanks – it was a privilege to have known you. I shall sorely miss you. And forgive me if I cry – I am only human, after all. And I promise you Alec – there will be no-one besides you in my life. You are the only one. And Annamarie and I, we will scatter your ashes at Vic Falls. As soon as we are able to. The two of us. With you.

Until we meet again, my darling Alec, until we meet again. May it be soon. Rest in Peace
Love (as always)
Pieter

PS: Blogfriends. Alec's Memorial Service is at 12:00 today. The text for his service is **I Corinthians 13.** *As we enter the Church, Josh Groban's* **You Raise Me Up** *will be played, and as we carry Alec's remains to the hearse, the* **Pie Jesu Requiem** *will be played. Alec's coffin will be adorned with a sheath of Orange Roses – his favorite.*

Notes: A courier arrived at 08:00 that morning, delivering the first batch of Peptide T I believed would save Alec's life. I remember opening the parcel, showing it to Heidi, and breaking into tears.

For Alec's Memorial Service, I broke all conventions. I remember when Mom passed away; we carried her casket into the church from the front. But when Dad passed away, we had to carry his casket into the church through the side door. Dad was going to be interred, so I had no problem with that.

But Alec was to be cremated. There would be no interment ceremony. And I wanted to give him his moment.

I discussed the possibilities with Dawie. Normally at a funeral the casket containing the remains of the loved one would already be in the church – taken in through the side door. We decided that we would carry Alec's casket into the church only once everyone was seated – through the front door and, not the side. Josh Groban's "You Raise Me Up" would play as we proceeded down the aisle.

Normally the minister chooses the text to read and the hymns to be sung. I did not want that. I know we were dealing with death, but I also wanted the piece that meant so much to both Alec and me to be read. I Corinthians 13. Dominee Fanie du Plooy admitted that it was a difficult text to use for a funeral service, but in the end he did a masterful job of it, lifting from the text exactly what Alec and I were about.

I recall carrying Alec's casket back to the hearse was the hardest part for me. Parting with him. I could not endure parting with him. I still can't.

After the service we carried Alec from the church while the moving "Pie Jesu" played, and each mourner was given the opportunity to place an orange rose atop the casket as a final farewell, before the hearse door closed one last time, and Alec was driven away.

Pall bearers? Annemarie and I at his head, RTS and Heidi at his feet, Joey and Ramona in the middle. The six people that cared about Alec the most.

In the end I am a broken man. I have lost the love of my life. I have lost two of my best friends – my Dad and Alec. In a short space of two months.

All because we did not know Alec's HIV status.

Opportunities lost, never to be had again.

When Alec and I started out our relationship, we meant to go for the HIV Test. On the 28th of June 2007 we decided to do it, but arrived at a clinic where the doors were closed. I remember saying to Alec that perhaps it was a sign that we didn't need to do it. We both agreed that we would trust each other that we were HIV–.

Trust was not enough. Had we gone for the HIV test we would have discovered Alec was HIV+.

Him being HIV + would not have changed my love for him.

But it would have enabled us to get him onto anti-retrovirals, to boost his immune system. It would have enabled us to still be together. It would have prevented this roller coaster journey from hell.

I remember being disappointed when I phoned Wits University's HIV Research Initiative, offering the Peptide T to them to do research on that and PML. They had not heard of PML prior to my contacting them.

I remember being disappointed when I scoured the Medical Research Council's website for research into PML and there being none.

I remember being disappointed when the HIV Research Initiative told me that there are more important opportunistic diseases than PML to concentrate on when it comes to research. It still eats away at me that, given 2008 HIV statistics, a potential of 118000 to 220000 people who may be affected by this disease, is “not enough” to warrant any research. It eats away at me like a cancer.

I have to live with this knowledge, day to day. I have to live with the knowledge that nothing I do will make the past undone. Nothing I do will bring him back. But maybe, by urging people to at least know their status and act accordingly, will help me ease the pain, prevent someone else a free ride on the roller coaster from hell. Nothing is for free, they say, it always has a price. This roller coaster journey is still claiming its price. You can prevent it, it’s easy. Know your status. Make people aware of PML. Ask your doctor if he or she knows what it is. You’ll be surprised to know how few actually do know.

I live my life according to two questions nowadays. The past few years have ingrained it into me, made it part and parcel of who I am. It honed me.

Have you loved your loved ones today, and not just said it?

Yes, it is easy to say I love you. It is something different showing it. Love is a verb, not a noun. It always has been for me, but I realise in hindsight that I took it for granted. I took it for granted that we would “live happily ever after”. We don’t. And you don’t know how long you will have your loved ones for.

Do you know your HIV status?

Knowledge is power. Because if you know you empower yourself to remain HIV– if you are, OR to keep your CD4 counts up and your viral loads down if you are positive. I think I am now more aware than ever of the HIV virus. I still have friends, wonderful friends, who are HIV+ and have been for a great many a year. And they are healthy and work hard at keeping it that way. But that is because they know, and act accordingly.

Life’s too short to have any regrets. But take my word for it; this one regret makes me wish that life was short indeed.

This book is a blog record of loving care during the treatment of a very special man suffering from an almost unknown disease called Progressive Multifocal Leukoencephalitis; PML for short. It is an opportunistic infection associated with HIV/Aids. The man was Alec. The author uses the pseudonym Lylo de Lange: Lylo is an acronym for “love your loved ones”.