

“We were in FIGHTING mode. We hadn’t exactly picked the winning ticket, but we had picked it anyway: time to face the FACTS and start our journey. One day at the time.”



You Tarzan me JANE

What to do when the **unimaginable** happens? **MARIE DEWEER** went through every parent’s worst nightmare when her baby boy was diagnosed with cancer. This is not a **SAD STORY** though, on the quite the opposite: it’s tale of **superheroes**, power capes and the silver lining!

Text Isabelle Vander Heyde - Photography Julie Vanderbaeghe

Ghislain was born in 2019 and our first year together was so wonderful. I actually consider him my own, special little treat –the sweet thing I’d always known would come a bit later on in life. Our eldest, Colette, was nine when he arrived and that was a very conscious decision. I had worked really hard in the years prior to his birth, developing and launching my own skin-care line and institute. I wanted a second child when I was older myself. Ghislain was to be our little reboot, our chance to start over and enjoy life to the fullest as a family of four. His first year coincided with the start of the Covid crisis and we actually spent lovely months together, getting to know each other and having fun in our little family cocoon. He was a happy baby, never sick, until that one morning when he woke up with a sharp pain in his neck. I knew from the way that he was crying that this wasn’t normal, but no doctor could find what was wrong. After three days of this hell, we ended up in hospital to run more serious tests. I was distraught seeing him suffer like this, but somehow, I wasn’t imagining anything bad. I’d been by his side for four days when my husband took over. The very moment I drove off however, he called me saying I had to come back, because the doctors needed to talk to the both of us together. I knew right then and there that it wasn’t going to be good news, even if cancer was the last thing I was expecting. I remember just how surreal the next few hours were. I faced four doctors who immediately drowned us in information, barely able to process what they said. They spoke about a tumour the size of an orange, of stage 4 cancer, of metastasis in his entire body and of a survival rate of only thirty percent. It didn’t make sense; I couldn’t see how they were speaking about my baby. The same little boy that was playing horsey on my knee as they were speaking, a bit high on morphine I must admit, laughing his head off. He looked so healthy and happy, and there they were telling me he probably wouldn’t make it. What mother can process that? That same night, we had



LA VITA E BELLA

The first night was tough. I didn't want to sleep because every time I closed my eyes, images of little coffins, flower arrangements and deceased babies appeared. It was like a horror movie I couldn't switch off, until finally another movie popped into my head. There's a scene from *La Vita E Bella* that has always touched me deeply: the father marches off to his execution in front of his son, acting all silly as if it's all just one big game. He doesn't want his son to be traumatized and keeps up appearances until the bitter end. I decided then and there that this was the parent I wanted to be: if we had to go through this, we'd do it marching. I didn't want Ghislain to have any traumas and that idea has kept me going all this time. What followed was one big party, covering up the dramatic march ahead. We would put on our favourite music in the car on our way to the hospital, decorate his room in different themes, dance in front of him when he was put under a general anaesthetic, invent special games for the hospital days, etc. It may sound strange, but I wanted it to be fun and involved everybody in that story. My daughter was Head of Decorations, the nurses had to sing along, Ghislain was the superhero. The medical staff has declared me crazy more than once, but this was my way of fighting for our family's survival. I knew the odds: my father-in-law had been diagnosed with stage 4 cancer a few years before and passed away within six months, and I certainly wasn't looking the other way. It is unbearable however to cloak yourself in misery for too long, and I don't think I would have done my husband and kids any favours by being miserably sad and scared all day long. We didn't waste energy either asking why: why us, why our baby boy? It is never fair, what good is it to stress about it? We were in fighting mode. We hadn't exactly picked the winning ticket, but we had picked it anyway: so, time to face the music and start our journey. One day at the time. No use looking too far ahead.

People keep asking me how I can be so strong, but honestly, I've never considered myself a tough woman. I just think that when something like this happens, there's some sort of primal maternal force taking over. It strikes me how I haven't

to move from the paediatric department to the oncology floor. As my husband and I were trailing Ghislain's hospital bed, I kept seeing a little coffin instead of a bed. I couldn't help it, I wanted to hit something or someone, the helpless feeling was just too overwhelming. My husband had to go home to our daughter. My boy and I were alone in an unknown environment, facing a battle we didn't know the first thing about. It felt very lonely. I went for coffee and spotted a Vogue magazine near the desk. I can still picture it to this day: Helena Christensen was on the cover and the tagline read "you're never alone". That's when my fighting spirit lit up again, even if it was only a hint of a flame. It struck me that I wasn't actually alone; I had a good husband, a great family, we would receive the best medical care, and our friends weren't going anywhere... I really wasn't alone: even Vogue said so! "I can do this," I thought, come what may.



felt tired this past year, I was barely hungry, as if I have no basic needs anymore. I'm continuously on high alert, living off adrenaline. Ghislain is now going through the final phase of his treatment, and I hope that when all this is over, I won't crash, even though I still feel strong as we speak. That's why I've decided to grant myself one day of self-care every week for the coming year. Ghislain will go to nursery and I will take some time to work out, hike, go shopping, have my hair done, etc. Time to do stuff I like, stuff that gives me energy. That is actually also a piece of advice the doctors gave us: to continue our lives as normally as we could, because once you give in, everything will spiral down very quickly. We knew that we were in it for at least two years and that we would never keep it together if we'd spend all that time in a cancer narrative. We had to stay in the hospital about three days every ten days. On those days, my place was with Ghislain -and I didn't want anybody other than myself or my husband by his side- but when he was at home, we literally stepped out of it. He stayed with a nanny, and I went to work. I needed to lead my life as I'd known and loved it: I enjoy working, I love my brand. I'm a mother, but also a businesswoman, a friend, a colleague and a daughter. I truly believe this life-work balance has helped to keep both me and my husband mentally sane. To keep doing things for yourself and for others is crucial, even when it may seem hard. When it was my mother-in-law's birthday for instance Ghislain was going through a rough time at the hospital. She's been such a rock through this whole experience and had lost her own husband to cancer, so I decided to treat her with a fun weekend in Amsterdam, just the two of us. I didn't abandon my child, Ghislain was with his dad and I wanted to do something for his grandmother. Did I feel guilty? No, because I knew I was doing everything I could and had to do for my child. I understood that granting myself these moments off would recharge me and give me the necessary energy to

keep up our fight. Ghislain's story has been documented on Instagram. The doctors advise against it, they say it's too confronting for the children when they get older. That's why I decided to share it in stories only. On the one hand it was a pastime, as I spent over 110 days in hospital alongside my sleeping baby boy. On the other hand, it was my therapy to speak openly and it also felt good to receive so many encouraging messages from mere strangers.

Some days are better than others of course and there were moments when I was about to get disheartened. Another family received the same diagnosis as we did, both around the same time. Our little boys started their fight together, but theirs sadly passed away last April. That hit me so hard, reminding me once again how my baby's life was literally just hanging by a silver thread. It was humbling to see how strong his mother, with whom I still have a good relationship, was. She fought for him until the very end, doing everything in her power to make his passing beautiful and serene. I think mothers don't realize how strong they actually are until something like this happens. In the darkest moments, when I feared I was going to lose Ghislain after all, I held on to the thought that heaven is filled with great mothers who have so much love to give, and that they would definitely love him and take care of him as I would have done. Whenever I felt the need to get it all off my chest, I had two friends I would call. Those were friends I had carefully selected because they weren't into the pathetic thing. I'd drive up to them, cry my heart out, they'd pamper me, feed me cake, let me speak, and I always left with a smile on my face and new-found energy in my heart. People often wonder how to react when something like this happens to a loved one. From my perspective the message is: stay calm and rationalize for me. Send flowers, have food delivered at home, take my daughter out for a fun day, but don't come telling me how sad and unfair and scary it all is. If there's one thing I can't stand, it's pity. We are not wretched because this has happened to us. I am not a sad sack and nor are my husband and children, they are so incredibly strong. I want people to say how brave they are instead of pitying them.



WHO'S LAUGHING NOW

The most difficult part medically was the therapy of eight consecutive chemo sessions that meant strict isolation for Ghislain -and thus, me too- for about eight weeks. All this time, crammed together in a small room, barely six meters by four. That's where I really pulled out all the stops and went completely loco with the game thing. Colette and I had chosen a jungle theme and went bananas with vines, monkeys and ... well, bananas! That room was really a sight to see, complete with different play corners, even a tent and a throne for him to hide on. I was really in the story there: he was Tarzan and I was Jane, stuck together in our little jungle, following our special routine. I actually had a complete routine scheduled: we'd start the day reading books in one corner, then singing songs in the next, then playing the 'food game'. Food was a tough one, because he was so nauseous from the chemo. Of course, that is the reason for most children having to stay eight weeks: they barely eat and need to be tube-fed. I was set on avoiding that at all costs. So, we made puzzles with his food, I drew figures in it, etc: whatever I had to do to make him eat. As I had packed a ridiculous amount of clothes for each of us we also had our dressing area. We'd wear different outfits every day, I wanted us to be dressed well instead of lounging in our joggers or pyjamas. I'm convinced that dressing up makes you feel stronger, no matter what others may think. So, there we were, stuffed in that tiny room in our extravagant looks, wearing our 'power capes'. I had little to no privacy, my bed stood next to his and there was only a small bathroom. Whenever he slept, I had access to an adjacent space where I could conduct online meetings and work. We didn't sing children's songs nor listen to kid's music -I don't think any adult would remain sane having to listen to Bumba 80 times a day for eight weeks in a row, haha! So Ghislain became quite the expert on the spring/summer '21 hits. Our favourite song was Who's Laughing Now by Ava Max. It's also the song we played whenever he was going under general anaesthesia, as I made it a rule he could never be drugged when he was crying. The doctor's face sometimes...

Ghislain heard the song on the radio the other day and his face lit up, as if it reminded him of some holiday in a forgotten jungle somewhere. My little boy has been a trooper and keeps amazing me. His very young age helps of course. This may sound weird, but he's grown accustomed to pain very early on. He was also spared the mental struggle an older child would have faced: not seeing his friends, missing out on school, asking mom the dreaded question if he was even going to survive this whole thing... It would have been a whole different story if it had been our 11-year-old. Colette's role is not to be forgotten in this story. We've been fairly honest without being brutally honest with her from the very beginning. She'd lost her grandfather to cancer some years before and became hysterical when she heard about her baby brother being ill too. She spoke to a psychologist a few times, but quickly made it clear she didn't need that. Like us, she had no need to linger in a sad story

for too long. Likewise, she told her teacher about what was happening, but asked her not to speak of it. My girl was really invested in our grand scheme and the games we played. She was in charge of decorating the hospital rooms and didn't take that task lightly. She'd think about themes, spend hours on Pinterest making mood boards, make me order stuff online to create her vision. Coming to the hospital was too hard, and I'm happy she could articulate that to us. She's actually been great at showing her emotions throughout the entire journey. The isolation episode was impossibly tough on her, so I had made her a box with To Do cards. Nothing complicated, just little missions to keep her going - phone grandma and tell her you love her, draw this, walk up to that spot, etc. Vice versa, she would always hide notes in our hospital luggage: little scraps of paper saying 'hang in there, mom, you've got this', 'I'm so proud of you', 'I love you and my brother, come on!' Basically, those were my words: she emulated the notes I sent her over the years when she left for camp, or spent a week at grandma's, or had a hard time doing something. Children really are like mirrors and everything you say or do comes around: it gives me goosebumps.

THE SILVER LINING

Now that we're nearing the end of the journey, the general question has changed from 'how can you be so strong' to 'how has this changed you'. It's funny because everybody assumes this experience has transformed our family. The answer is **it hasn't. I fully appreciated life long before** Ghislain got ill. I could tell you it's not important to work all the time, that material things aren't everything, but I actually still enjoy working and getting all dolled up. I like pretty things, that's just who I am and have always been. We were already a very stable and close-knit family, and I was always happy with the way we approached life. Now that Ghislain's therapy is coming to an end, we're scheduled for a final conversation with the oncologist. To tell you the truth I'm not looking forward to that, because he'll tell me all about the risks and struggles that will follow. I'm not interested in statistics and prognoses. Life is a flow, you never know what's coming: something could happen to Colette overnight, or to me or my husband, it's simply not something you can predict. And you're not really living when you're focussed on these things. If we had known on the day he was born that Ghislain would become so very ill, would I have been able to enjoy his first year? Would that beautiful time have been possible, my little treat? Never! You have to live life to the fullest. The great thing is that I already understood this before my son got ill. I'm satisfied with who we are, my children are brave, and I like the way we tackle life. We live like there's no tomorrow. And that is the end of it.