WHAT I'VE LEARNT

YAEL COHN

PICTURE **ANDREW TAUBER**

As personal assistant to Molly Meldrum for 12 years and as a music manager, **Yael Cohn**, 42, knows something about dealing with pressure and being busy. She was by Meldrum's side during his long recovery after his life-threatening accident at home in December 2011. But nothing prepared Yael and her partner Edan for the long, frustrating and often painful journey towards finding a diagnosis for their young son Maximus. After countless visits to doctors and specialists, there is still no diagnosis. Cohn has learnt a lot about determination, resilience and love.

The first time I thought something was possibly wrong was when I was breastfeeding Maxi when he was about nine months old. I looked into his eye and saw what we later found was a tumour. Thankfully, he no longer has a tumour. But then at about 16 months old, he started getting these "moles" on his skin and was diagnosed with Juvenile Xanthogranuloma, an extremely rare blood disorder. And then I tried to lift him one day and it was incredibly difficult. I took him to the doctor who just said he was a happy, healthy child.

I monitored him. Took photographs. Then he began regressing in his mobility and the weight gain was incredible. In six weeks he gained a whopping 2kg and I was certain this was not food-related — you cannot possibly feed a child that much.

He reverted to crawling after he'd been walking, and I could see his frustration. He went from knowing he could do things to not being able to do them.

The doctors said he was riddled with lesions in the core of his brain. I said to them "Well, let's kill this disease. How are we armed to kill it?"

The response was, "We don't really know." They said: "It's too complicated, there are a lot of abnormalities within the brain, we can't explain at this point what it all means." We tried to link some of his symptoms: he's got high blood pressure, he's got brain lesions, he's got skin lesions, he had an eye tumour, he's got serious weight gain, he's got serious mobility regression ... so what is wrong with my son? Do any of these actually link? Apparently not.

As a mother and father, we cannot accept when someone says, "We do not know what's wrong with your child." It's not good enough. This is how spoiled we are with modern medicine — we do expect it to give us all the answers.

The doctors — and they are fine doctors — still don't know. Do you know how frustrating it is to walk in and out of hospital and have more and more tests and departing those visits every time with the same unknown result?

Maxi is 2½ and he is already morbidly obese at 25kg. It is incredibly frightening and frustrating dealing with the unknown.

Maximus is one of many children around the world who are undiagnosed and, as a result, they are prone to falling through loopholes in the system. Without a diagnosis, there is little support available.

Some diseases are so rare there are no tests yet invented to find them. If, by miracle, a diagnosis is made and an orphan drug (a medicine that is intended to treat, prevent or diagnose a rare disease) should be required, it can be very difficult to convince a pharmaceutical company to invest in a product that is not produced for the masses.

Under the disability support systems, you are at a disadvantage if you don't have a medical diagnosis to explain your child's condition. You cannot access a lot of services and funding unless you tick a box with a label yet all the research states that the best way to help children with disabilities meet their full potential in life is through early childhood intervention services.

We felt it was important to share some of our struggles and joys as this may inspire, help or somehow make a difference for other parents going through similar situations. Having spent the past two years engulfed in all areas of Maxi's illness — caring, researching, advocating, attending appointments — I realised something was missing. I missed my peers.

Thanks to the many friends, family and charities that have helped us finally put in place all of the necessary equipment, activities and childcare for Maximus, we finally felt secure enough for me to take the plunge to go back to work. It was a difficult decision, but I realised that without the work/life balance I was becoming too engulfed in every little detail in trying to cure Maxi.

I chose to do the easiest job in the world for me, which is managing an artist. Easy because it's my true calling and passion. I am so proud to be representing Ben Hazlewood, a talented and handsome singer-songwriter, who was a finalist in *The Voice* last year. And it's made the world of difference to my confidence.

Without Edan — my man, the love of my life, the father of our beautiful sons Maxi and Jacob (who's five) — I don't know how I could have had the strength to get through all this. He holds me up when I fall. When I am lost, he leads me back on track. Together, we are unstoppable in our war against this mystery illness.

Molly (Meldrum) has been incredible and I feel so fortunate he is willing to step up and help where he can. As a public figure he has brought awareness, which helps not only Maxi, but many other families who are similarly suffering.

Molly is my best friend. I was there for Molly after his accident and he's there for me. He said he loved Maxi like his own son. His support means so much.

Since Maximus's first signs of illness, many things have changed. Jacob and Maximus have given me a whole new approach to life. If a project falls through or everything goes pear-shaped, I put it in perspective and it means nothing at all. And when people in the street make ignorant or offensive comments about Maximus, I just feel happy that I am one of the lucky ones — I can see what they cannot. I can see how wonderful, brave, inspiring and adorable our boy truly is. And that makes me smile.

as told to PETER WILMOTH

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