

50 of the bravest dreams

Lisa Holland, 46, watched in awe at the incredible courage of her husband and little girl...

We sat in the small doctor's office, our mouths dry and our heads full of babies yet to be born.

Like most couples who were madly in love, my fiancé Nigel and I wanted to start a family. But while some people come to see doctors about what help they can get to have children, we had come to hear whether we should have them at all. 'It is difficult,' the specialist said, looking at Nigel, 32.

'Yours is the first case of CMT we know of in your family,' he said. 'So it is impossible to trace it. The best I can do is make an educated guess.'

CMT is Charcot-Marie-Tooth disease, which is a degenerative disorder affecting the nerves in both the legs and arms, slowly and relentlessly robbing them of all their strength.

Nigel's parents had noticed something wrong when he was just four years old because his toes curled inwards. He was 10 when CMT was finally diagnosed. As the condition is hereditary, passed from parent to child, we had come to see this geneticist to discover the odds of our children getting it. 'I'd put them at 25%,' the specialist said. 'But that's only guesswork.'

We decided 25% didn't sound so bad. Nigel and I had been together for two years and he was living a full life working as a photographer, despite the condition. I was a nurse and I knew that CMT wasn't life-

threatening. So to me, it wasn't the end of the world.

Six months later, in April 1994, we got married and three years after that we had a baby boy. We named him Matthew and, thankfully, he stayed healthy. His sister, Amy, arrived two years later, also free of CMT. But we didn't once think that having another child would be pushing our luck, even though Nigel's condition had begun to deteriorate. He was now having to use a wheelchair on days out and crutches occasionally around the house. Not being able to change nappies and dress our children frustrated him. But he had

something that CMT couldn't take away – determination.

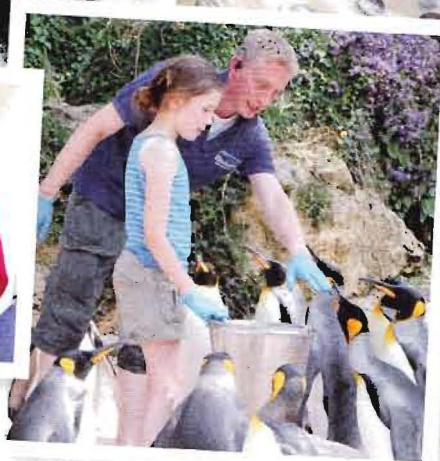
I fell pregnant again in 2001 and Ellie was born, beautiful and weighing 8lb 2oz. The first shivers of worry came when she was a toddler. She tired easily and, by the time she was four and about to start nursery close to our home in Wellingborough, Northamptonshire, Nigel was worried. 'Ellie isn't walking properly,' he said. We were referred to a paediatrician who confirmed that Ellie did indeed have CMT and a mild learning disability. That made me angry. Wasn't one condition enough? Yet Ellie had inherited Nigel's



Together as a family...



From the heart



determination. So despite the terrible news, we saw such incredible strength in her. Nothing stood in her way. At school, she made friends easily and had a flair for art, and a love of all things pink. She declared she wanted to work with horses when she grew up – and marry all of One Direction!

But as Ellie got older, Nigel's health continued to deteriorate. CMT was now affecting the nerves of his vocal cords too, making his voice little more than a whisper. He could no longer walk at all, nor stand unaided. But with his 50th birthday approaching, he was determined to celebrate.

A growing list

'I don't mind growing old so long as I never grow up,' he announced, and Ellie giggled. His little shadow had just turned 10.

And with that he announced he wanted to do 50 things to celebrate turning 50. A friend had done the same for their birthday and Nigel had loved the idea.

'What things?' I asked him, so we sat down and made a list.

'Catch a big sea fish,' he said. 'I've always wanted to do that. And do a bungee jump.' I didn't like the sound of that one. 'And

meet John Cleese!' he laughed. Before long, everyone who heard about it had a suggestion. The list grew and grew. Sail a boat... Scuba dive... Lose weight... Write a book... Learn to make crème brûlée...

I breathed a sigh of relief when enquiries deemed the bungee too risky for Nigel. But in February 2012, 10 months before the big 5-0, all five of us got ready to watch him do his first task – an indoor skydive.

It was surreal. There I was with the children, waiting to watch my husband, who couldn't stand unaided, be hurled through the air.

But Ellie was so excited and before Nigel headed off, she came to a decision of her own.

'Daddy, I'm nearly 11,' she told him very seriously. 'Could I do 11 special things too?'

'Of course you can,' he said. And I smiled, though a big lump was forming in my throat.

I was thinking, why did we ever worry about Ellie? She was Nigel through and through. Special, plucky, strong and wilful.

And so, back home, Nigel on a high from his incredible dive, we started to make her list, too.

Feed a bird from my hand... Learn to make macaroons... Swim a length of a swimming pool...

She wasn't too keen on the last one. 'But you've got to push yourself,' Nigel told her. 'That's exactly what a Big List is for.'

And five months later, on Ellie's 11th birthday, the family gathered once again. This time it was to watch her feed penguins by hand at a bird park in the Cotswolds. I'll never, ever forget the look of joy and triumph on her little face.

And now Nigel and Ellie are storming through both their lists.

In fact, Nigel has just three more to go. He's yet to meet John Cleese, and though he's been sea fishing, a big catch eluded him. He is still waiting to have one of the photos he

has taken published in a national newspaper. Ellie is busy too and is planning to walk over the O2 Arena.

Nigel and Ellie's symptoms will gradually worsen but there are drugs that will help them to live a long and full life. I feel so lucky to be blessed with this amazing family – and in four years time it will be my 50th.

'Will you do a list, Mummy?' Ellie asks me. Maybe. Fifty beaches with 50 cocktails sounds like a good one to me. But I leave the heroics to Nigel and Ellie. They may have CMT, but they were born to inspire, that's for sure. ♦

'I feel so lucky to be blessed with this family'

Nigel and Ellie's top 10 achievements

Nigel

- ◆ An indoor skydive
- ◆ A scuba dive
- ◆ Ride in a hot-air balloon
- ◆ Play the drums
- ◆ Go to the Proms
- ◆ Make a clay pot
- ◆ Steer a narrowboat
- ◆ Give a talk as a guest speaker
- ◆ Complete a 1,000-piece jigsaw
- ◆ Write a book
- ◆ Meet a Formula 1 team

Ellie

- ◆ Visit a zoo
- ◆ Ride a horse
- ◆ Learn to make macarons
- ◆ Raise money for CMT
- ◆ Create a cartoon character
- ◆ Swim a length of the big pool
- ◆ Make a clay pot
- ◆ Feed a bird by hand
- ◆ Visit Madame Tussauds
- ◆ Plant, grow and eat strawberries

◆ **The 50 List: A Father's Heartfelt Message To His Daughter (£7.99, HarperCollins) is out now**

◆ **September is Charcot-Marie-Tooth Awareness Month. Visit cmt.org.uk**