WHAT IT FEELS LIKE... ...TO FIND OUT ONE OF YOUR TWINS WILL NEVER WALK

LIZ LOCKLEY'S SON GEORGE HAS SPINAL MUSCULAR ATROPHY, A CONDITION FOR WHICH THERE IS NO CURE. HIS TWIN, HARRY, IS UNAFFECTED. WHERE DO THEY GO FROM HERE?

To the rest of the world, my life seemed perfect. Until a few months ago, I would have said it was, too. I married James, my university sweetheart, in December 2009 and, a few months later, I found out that I was pregnant with twins. The boys, George and Harry, arrived in January 2011 – they were beautiful, everything we had hoped for. They weren't identical, but I had bought two of everything – they looked like peas in a pod in their outfits. George was the leader: he learnt to do everything first, whether it was lifting his head, rolling over or sleeping through the night. Before long, Harry would follow suit.


Incredibly close George, left, in a supportive chair, and Harry

Every day, it seemed, something new happened – but, at nine months, George's progress began to plateau. A child's first step is a milestone, but, as Harry wobbled onto two feet, I became increasingly concerned that George had not. Then George stopped crawling. Everyone kept telling me I was worrying unnecessarily, but I knew something was not right.

Two months later, James and I were sitting in a room at Great Ormond Street Hospital, being told that our son had spinal muscular atrophy (SMA) type II, a muscle-wasting condition that meant he would never stand up, never walk. A chest infection could end his life. We were told that there was no treatment and no cure. Our world fell apart.

One of the cruellest aspects of this condition is that you are handed a bright-eyed, healthy baby and, a year later, told that they are going to be severely disabled. I had never imagined that something like this would happen to us. Although George's condition is the most common genetic cause of infant death, neither of us had heard about it before. Few people have, yet about one in 40 of us carries the faulty gene. As it happened, both James and I are carriers, which means our children have a one in four chance of being affected. We didn't know, and nobody in either of our families has the condition. George's consultant explained that we had simply been unlucky, but accepting news like that is hard.

INTERVIEW: FIONA WILSON. PHOTOGRAPH: LIZ LOCKLEY

My head started to fill up with all the things George would never be able to do, such as ride a bike, play football, climb a tree or just run a race against his brother. He will never be able to live a fully independent life. It didn't seem fair – George didn't deserve this. I went through a period of mourning for the loss of a life I thought that we, as a family, would have. I wrote down some of my thoughts during that time; looking back now, I can see how raw my feelings were.

GEORGE WOULD NEVER STAND UP, NEVER WALK. OUR WORLD FELL APART

I remember seeing other families setting off for a bike ride, and I couldn't help thinking that should have been us. At playgroup, I remember the children singing If You're Happy and You Know It. I loved watching Harry's face as he eagerly stamped his feet up and down, but I also felt overwhelmingly sad when George looked at me, confused about why he couldn't make his legs do the same.

The life that James and I had dreamt of for our family was suddenly taken away, but we had to be strong: we had so much to learn and so many challenges to face. Top of that list was getting George mobile. Some reports show that people affected by SMA have above-average intelligence, and mobility is crucial to any child's cognitive development. Unfortunately, the NHS is unable to provide the latest mobility aids for George. A SnapDragon power chair, which costs £19,000, would allow him to move forwards, backwards, up and down, and remain in a standing position. It would mean that, instead of looking longingly at the world around him, he could investigate it for himself.

We tried out the chair a few weeks ago. I was worried about how I would feel, seeing him in a wheelchair for the first time, but I couldn't help but smile when I saw the big grin on his face as he moved about and gained some freedom at last. There was even a platform for Harry to ride on.

My boys are incredibly close. I have been amazed at their understanding of their abilities and limitations at such a young age. George has already learnt how to use Harry's mobility to his own advantage – if his favourite toy bunny is out of reach, he knows just who to ask for help. Harry is always willing to oblige. The horrible irony of the situation is, of course, that George will grow up unable to do many of the things he will see Harry, his twin, doing. But much is being discovered about the condition every year. We will find our way.

I do worry about the future: how will George cope at a mainstream school? How will his needs intensify as he gets older? How will I help him become the person he wants to be? Our life is going to be very different from the one I had hoped for, but this doesn't mean it will be worse. We will have to find new ways of doing things and build new dreams together that meet the needs of both our boys.

Some days are still a struggle, and I do sometimes think "Why us?", but I know I have a lot to be thankful for. I have two wonderful little boys. George's diagnosis has made me realise what is important in life. Many challenges lie ahead for us, both practically and emotionally, but throughout all this George has continued to smile. That, more than anything, is what has given me the strength to stay positive.

To learn more about spinal muscular atrophy or discover more about George, visit aboutgeorge.co.uk