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Pride of Britain

Kirsteen Lupton and family, with Jeff Hudson

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About the Book

I know I'm lucky to be alive. I know I'm lucky to have such a wonderful family. I don't like to dwell on negative things. I'd rather enjoy my life as much as possible. I've got my school, my friends and home, and I'd like to leave it at that ... Maybe I'm being naïve. Maybe I'm just bottling everything up and one day it's going to explode out of me. But at the moment I'm okay with it.

PRIDE OF BRITAIN

Kirsteen Lupton and Family With Jeff Hudson



This book is dedicated to the staff of Great Ormond Street Hospital for Children

AUTHOR'S NOTE

This book is written by me and my family. Without them I wouldn't be alive today. Because I was so young, I don't know a lot of the details about what was wrong with me. I thought it would be best if they told the stories themselves.

Foreword

I first met Kirsteen in 2006 when, quite rightly, she was awarded a Daily Mirror Pride of Britain award.

Why was she there? Simply because she is an extraordinary young woman, beautiful without, and beautiful within. Some are born 'special' through privilege. Some are 'special' because they have an innate talent. Kirsteen is 'special' because of her spirit. This book is her latest venture to raise money to help other children who have suffered physically, like her, and who have spent endless years in and out of hospital. Her story is inspirational. Take time to read it; I believe it will perhaps make you see the world in a different way, bring more kindness into your life, and bring smiles and sunshine on even the bleakest day.

On October 27, 1993, Kirsteen Lupton was born in Glasgow to Jill and Martin Lupton. Born with her bladder outside her body, Kirsteen was just a few hours old when she underwent emergency surgery. A day of joy had turned into one of fear and helplessness. It would not be the last.

Through the years, Jill and Martin have been regular visitors to hospital, as Kirsteen has endured numerous operations. They have watched their little girl live with terrible pain, not knowing what to do for the best, listening to her cries. Theirs is a story of courage and pride, as they have watched their very ill daughter grow into a stunning young woman. Over the years, Kirsteen has been looked

after by the staff at Great Ormond Street Hospital in London. As she grew, she became determined to raise money for the hospital. To do this, she has given some very brave speeches, modelled at a fashion show, arranged for the proceeds of her school play to go to the hospital and many other things besides. At one event she raised £20,000 in just ten minutes by auctioning her own signature.

'I would do anything for Great Ormond Street,' she says. 'Because I've grown up seeing so many sick children, it makes me stronger to help raise money as a thank you to the hospital. I want to be a doctor and would love to work there.'

Kirsteen will have to use a catheter for the rest of her life, but her spirit remains undaunted. The day I met her she was busy charming a room full of people. As she received her Pride of Britain award, she spoke so beautifully of those who have helped her. Movie star Jude Law fell in love with her, saying she gave hope and inspiration to everyone. McFly, the band of the moment, gave her a signed guitar and the then-Prime Minister Tony Blair invited her to Downing Street the next day. Now that was a great day for any girl.

I believe that Kirsteen has an outstanding future ahead of her. She is special because of the devotion of her family and her courage. Through it all, she gives so many others hope. She makes the difference and I wish her every happiness in the world.

Carol Vorderman 2008

Prologue: Save Me

KIRSTEEN LUPTON: 'SAVE me! Save me! Don't let them kill me!'

I was seven years old when I screamed those words.

Seven years old and terrified. I looked desperately up at Mum and Dad from my hospital bed. They were crying too. I wanted them to reach out and pick me up and make it all right. I wanted them to cuddle me – anything to stop the doctors taking me away.

'Help me!'

But it didn't matter how loudly I screamed. They couldn't cuddle me. There was nothing they could do as I was wheeled towards the operating theatre. I weighed one and a half stone, I hadn't eaten for four weeks and if I didn't have this operation I could be dead within days.

But you don't think rationally when you're ill.

'Please! Mummy, Daddy - save me!'

I heard their voices. They kept saying, 'It's going to be all right, don't worry, Kirsteen. It's going to be all right.' But I wasn't listening. I was too scared.

And I wasn't the only one.

Two nurses were watching as my bed was pushed away. I looked helplessly up at them but they couldn't look back. They were shaking, holding each other. Both of them were sobbing their hearts out.

That's when it hit me.

'If the nurses are crying - if they're scared - then they must think I might not be coming out.'

Oh God, no!

'Save me! Save me!'

I had to be held down as the anaesthetic was administered. Seconds later I was unconscious.

But I had seen the question in the eyes of the doctors, the nurses and Mum and Dad. The question was – would I ever wake up?

Would I come out of the operating theatre alive?

CHAPTER 1

There's a Problem

KIRSTEEN: I WAS born on 27 October 1993 in the Queen Mother's Hospital in Glasgow. It should have been the happiest day of my mother's life. She was getting the daughter she'd always wanted. She already had two beautiful boys, Kenneth and Martin Jr, born three and one and a half years earlier, respectively. But something had been bugging Mum all through this pregnancy. Something she couldn't put her finger on.

JILL: Nobody would listen to me. There was no evidence to support it. But I didn't *think* there was something wrong; I *knew*.

I told my husband Martin early on.

'What do you mean?' he asked.

'There's something wrong with this baby. I just know it.'

He tried to reassure me, but I was adamant. With my first two babies I had felt different somehow. I couldn't explain it. It was just a feeling. I've never had one like it before or since. But it was so strong. I just knew.

The next day we went to the Queen Mother's Hospital for another scan. Just like before, the results were fine.

'See,' Martin said. 'There's nothing wrong.'

But I knew otherwise. We went for five scans in total: the usual two, then two more when I expressed my fears and another the day before I gave birth. I even had a procedure called an amniocentesis to test for Down's syndrome, spina bifida or some other genetic abnormality.

It's not a nice experience. The doctor puts a long needle through your tummy and draws off some of the amniotic fluid that surrounds your baby. There are other downsides too: there's a slightly increased risk of miscarriage; and it also takes two or three weeks for the tests to come back. My results came back clear, though. Another tick in the box marked 'Normal'.

But still I wasn't convinced.

One thing we did learn from the scans, though, was the gender of the baby. 'You're having a lovely, healthy little girl, Mrs Lupton,' I was told, although I didn't have too much faith in that either. When I was expecting our second child I asked if they were able to tell us the baby's sex. It was just for practical reasons, really, because I wanted to know whether or not young Kenneth's old clothes would do or whether we had to buy some new little outfits.

With a big smile on his face the doctor told us, 'I'm ninety-seven per cent certain you're having a little girl.'

Oh, that's nice, I thought. One of each. And, of course, it gave me an excuse to go shopping.

But when we left the hospital Martin said he wasn't convinced. 'I can't put it into words,' he said. 'I don't have any reason for it but I just feel there's another little boy in there.'

And when Martin Jr popped out four months later, he was proved right.

Everyone pooh-poohed my worries about the third baby, especially my mother.

'Don't be so stupid,' she snapped. 'You've had all the tests and they've picked up nothing. We'll hear no more of this silly talk.'

But I knew.

MARTIN: When Jill went into labour with Kenneth, our first little boy, the midwife became concerned about the

baby's health. 'He's getting too distressed to come out naturally,' she told us. 'We're going to have to bring in the doctors.'

She made a phone call, and a short while later Jill was being wheeled into an operating theatre for an emergency Caesarean section. We were assured that it was a perfectly normal procedure, but everything about it felt very abnormal to me.

I was allowed into theatre with Jill, but I had to get changed into blue surgical 'scrubs'. And whereas we only had one midwife with us before, suddenly there were about a dozen people in the room.

And there were so many lights and machines it looked like a scene from *Star Trek*.

Exactly the same thing happened when Jill went into labour with our second child and, once again, she was rushed into theatre.

So when Jill fell pregnant for a third time the doctors told us, 'There'll be no risks taken with this one. Your baby will be born by C-section – no argument.' So at least this time we knew what to expect.

'But,' he went on, 'nobody should have more than three Caesareans. The body can't withstand it, so you should consider this your last child.'

That was fine by me and I think Jill's instincts were the same. We'd never really discussed it before then, but I'd always felt that two or three children would be just about perfect. So when it was spelled out to us like this it seemed perfectly all right.

The night before Kirsteen was born I dropped Jill off at the Queen Mother's and helped her to settle in. She felt most uncomfortable being there and let me know it.

'What am I doing here?' she complained. 'I feel such a fraud. I'm not even ill.'

She couldn't see the point of taking a bed from someone who might really need it. But that's Jill all over.

The boys were at Jill's parents in Old Kirkpatrick that night so that's where I headed. Kenneth was three at the time and Martin Jr was one and a half, and although they weren't entirely sure what was going on, they were excited at the prospect of getting a little sister. The main thing, as far as I was concerned, was to make sure they didn't feel left out.

We had dinner and then the boys were allowed to stay up later than usual to play in front of the television as a special treat. I didn't pay much attention to what was on the screen because I was chatting to my in-laws and trying to keep the boys out of mischief. But I suddenly became aware that what was showing was a documentary about childbirth.

We turned up the sound and then sat there mesmerised for a few minutes. The programme was about a condition that caused babies to be born with some of their organs on the outside of the body; the doctors said they did not know its cause, but that it was becoming more common. I'd never seen anything like it. The programme was quite graphic and I found watching all these poor babies being treated very upsetting. I gave it a few minutes then had to switch channels quickly. It really wasn't the sort of thing the boys should be exposed to. And it definitely wasn't something I wanted to be watching the night before my wife gave birth to our daughter.

JILL: It's hard to sleep in hospital, especially when you're thirty-eight weeks gone, so I was up nice and early on the morning of the planned operation. When Martin arrived he filled me in on what the boys were up to, then we got ready to go down.

It was odd knowing that we were going into theatre. When you have a baby naturally you don't have a clue when or how things are going to happen, but you assume that

you'll be in bed, not on an operating table. Then, when they do start to happen, you just have to sit back and wait till it's all over. You don't normally get a chance to worry.

The previous two Caesareans hadn't been planned at all but we had got through them, and they were good experience for this one. We were more excited than nervous. I suppose you could say we were even a little blasé. Can you blame us? I had a history of two lovely pregnancies and two fairly straightforward operations, and this one looked like being the same. So if I didn't actually say it, I was certainly thinking, 'Oh, I know what I'm doing – this is easy.' I was so confident. I even remember thinking, 'Well, I hope I'm out in time for Hallowe'en night for the boys.' That was my main concern. We knew we were going to have a wee girl and we knew our way around a C-section. I felt there was nothing that could surprise us now.

Even my underlying belief that something was wrong didn't trouble me unduly at this point. I know that sounds odd, but I'd got used to feeling that there was a problem. I'd dealt with all those emotions weeks before. There was nothing I could do about it now. It was in fate's hands. We all were.

There was nothing to do but wait.

MARTIN: The operating theatre at the Queen Mother's felt like familiar territory by now. Jill didn't seem worried and I certainly wasn't. I hadn't given a second's thought to her predictions – if I'm honest I thought her hormones had been getting the better of her. I'd even been a little bit scornful in the car on the way over to the hospital the day before when she had mentioned it again. 'For God's sake,' I told her, 'stop it. You've had all the tests. Everything's fine.'

The nurses in the theatre did as much as they could to put us at ease while they fixed up the surgical screen across Jill's middle and the anaesthetist went to work. I wasn't going to be able to see anything until they were finished. This was standard practice, of course, although as a policeman I've seen more than my share of blood.

I took my 'usual' seat by Jill's shoulder and we waited for the process to begin. As far as I was concerned, everything had been fine during the pregnancy, it was fine now and it was going to remain that way.

It's odd seeing so many people in surgical gowns peering over your wife's body, all very busy, focused on their jobs. My role was simply to assure Jill that everything was all right. I don't know if she was listening but she seemed remarkably calm. If anything, I was the one who was beginning to feel a little anxious. But, I told myself, we were in good hands.

Kirsteen's delivery was very straightforward. I remember looking at my watch. It was eleven o'clock. Bang on schedule.

Now was the time to be excited. I watched as they lifted the baby from Jill and above the screen to where we could see her. Jill and I exchanged glances that said, 'We've done it!'

I'll never forget that moment. The wee mite was covered in blood and there was a large swirl of umbilical cord around the abdominal area, but she was the most beautiful little girl I'd ever seen. And in a few minutes I'd be able to hold her in my arms and tell her that myself.

As a man watching a birth, you can feel very left out. All eyes are on the mother and then the baby. If the father disappeared in a puff of smoke halfway through, I don't think anyone would raise an eyebrow.

As soon as the baby comes out, the surgeons show him or her to the parents then whisk the little one off to a table where they run through all sorts of tests. Kenneth had a touch of jaundice when he was born, which, along with various other things, can be picked up within seconds. Babies delivered via C-section also need to have their

muscles massaged a little because they've bypassed the stretching that usually occurs in natural childbirth.

But this is the point at which it pays to be the partner during a Caesarean, because Dad gets to watch all of this. He sees up close the first moments of life, the first gulps of air of the new arrival. And while the mother is still being stitched, he can give the baby the cuddle he's waited nine months for. That's how it was with Kenneth. That's how it was with Martin Jr.

I got up to watch as they cleaned Kirsteen and ran through all the usual tests. I'd seen the routine twice before and I knew this was where I could join in. But as I followed my little baby girl over to the table, one of the doctors turned towards me and held me back.

'Why don't you sit down and wait with your wife, sir?' he said, and without questioning it I did.

Jill was still being stitched at the time. I shrugged as I approached her and told her they'd asked me to hold fire. 'Some new procedure,' I said.

Jill said nothing, and as we waited in silence we both tried to catch a glimpse of our little girl, surrounded as she was by a group of five medics.

The minutes passed so slowly. But soon a young doctor left the group and approached us. I stood up to meet him.

'Mr Lupton,' he said, 'congratulations. You have a beautiful baby girl.'

I could hardly stop the feeling of pride that was rising inside me. But the doctor managed it.

'Unfortunately,' he went on, 'there's a problem.'

Time stood still for me right there and then. I struggled to take the words in but they made no sense to me. I wasn't expecting them. It was as though the doctor was speaking a foreign language.

I glanced at Jill as the doctor's words echoed around my head. There's a problem.

'What kind of problem?' I finally managed, terrified.

'We think we can see her bladder.'

What do you say to something like that? No words would form in my mouth. I felt so helpless, like I'd been punched in the stomach. Jill and I looked at each other and I felt tears begin to well. Jill was silent too, but seemed unusually calm. It had to be the anaesthetic, I thought.

I desperately tried to make sense of everything. I remembered seeing Kirsteen's stomach when she was lifted out. There had been something on her abdomen that looked a bit like a peeled tangerine. Was that the problem? I remembered thinking it was part of the umbilical cord. But I'd only caught a fleeting glimpse and it had genuinely made no impression on me.

I realised the doctor was still speaking.

'... now, we don't know what the ramifications of that are,' he said, 'but the consultant from Yorkhill Hospital will come and speak to you.'

I nodded, but something was niggling me, something at the back of my mind. Why wasn't I more shocked? Then I remembered the TV documentary from the night before.

Do you ever come across contrived coincidences in literature or in film and feel that you've been short-changed, that the writer has been a bit lazy with the plot and that things never happen that way in real life?

Well, it was happening to me. Just one day earlier I had never heard of a child being born with its organs on the outside of its body. Now, not even twenty-four hours later, I was being told it had happened to my own daughter.

I do wonder whether my reaction to the news would have been different if I hadn't seen that documentary. As it was, I was stunned, and the wind was absolutely knocked out of me, but I was somehow keeping a measure of control over my emotions.

I slumped back down in my chair to digest the news. I knew the tears weren't far away.

Jill's prediction came into my mind. How could she have known and yet the scans had not picked anything up?

Out of nowhere I heard a friendly Australian voice. It was the surgeon who had delivered Kirsteen. He and his colleagues were still working on Jill. Taking the baby out is just the first step in a Caesarean. It can take up to an hour before Mum is ready to leave theatre.

'It doesn't look too hard to fix,' he said. 'It just looks like a bit of minor damage to the abdominal wall. There's nothing much to worry about.'

The feeling of relief at that moment was incredible. And that's when the tears finally arrived.

'It's going to be all right,' I told Jill, who still had more control over her feelings than I did. 'They'll sort her out. It's going to be all right.'

I squeezed her hand as I spoke and smiled through the tears, but I don't know if my words were meant more to calm her or me.

JILL: That news from my surgeon was so welcome. Thank goodness, I thought. It must be no big deal.

But then a few minutes later he let himself down in my eyes when, having just put our minds at rest about Kirsteen's condition, he leaned over and asked, 'Are you sure you want me to go ahead with the sterilisation, seeing as you've got a disabled child?'

Before going in I had been advised to undergo sterilisation after delivery as this would be my third Caesarean, and the maximum doctors recommend. I was expecting it. But there I was, lying helpless on an operating table, having just been told that my baby has a problem. I was utterly confused by what was going on and was being asked this question.

'You have to make up your mind now,' he said. 'Do you want me to go ahead with it or not?'

I said, 'Yes. Of course.'

To me, it made no difference. It wouldn't have altered anything if Kirsteen had been perfectly healthy or if, God forbid, she'd died. I wasn't having three children for the sake of it. I didn't want any more. My body probably couldn't handle it. But what right did this man have speaking to me like that? His insensitivity made me feel worse somehow than the news about Kirsteen. At least that sounded as though it was easy to put right.

How wrong I was.

I was still being seen to when a new figure stepped into the operating theatre. Martin saw him first. It was obvious he was important from the way the other doctors and surgeons greeted him. He came over and introduced himself to us as Mr Alasdair Fyfe, consultant from Yorkhill Hospital. (Yorkhill and the Queen Mother's are joined to each other by a link corridor.)

He wasted no time in getting to the point. I think he was used to people hanging on his every word. And, to be honest, anything he had to say we wanted to hear.

The first thing he said was that Kirsteen had a condition called 'bladder exstrophy'. This occurs when a pelvic bone fails to set properly, allowing the bladder to form outside the body. But he also added some good news, and told us, 'What I can say to you from the outset is, it's not life-threatening.'

Our relief at this point was palpable, only he wasn't finished.

'But you have to understand this: of all the conditions it is possible to do something with, this is the most surgically challenging.' He was looking at us closely now. 'Every case is different but your daughter will never be naturally continent, she'll never have a working bladder she's got control of. She'll never have a normal life.'

My heart sank with these words. And then he dropped the bombshell.

'She's going to face an awful lot of operations over the next few years. The first procedure will be a fairly lengthy process to enclose her bladder. And I want to do it today.'

I couldn't believe it. Our little girl – who we hadn't even touched yet – was going to have an operation. She was less than one hour old and she was being taken from us.

The emotions that I'd managed to keep in check so far came flooding to the surface. If Martin hadn't been there I don't know what I would have done. I was screaming and sobbing and crying out for Kirsteen.

'Oh that poor wee baby. My poor little girl!'

MARTIN: As a policeman, I've seen a lot of horrible things. I'm probably a bit more matter-of-fact about difficult situations than a lot of people because that's what regular exposure to unpleasantness does to you. But when something like this happens to you, when it's brought to your own doorstep, it's another story.

I felt like a child again. I didn't know what to do. I was horrified, numbed, sad. And fearful. What was going to happen to my little girl? A gamut of emotions swirled around inside my head. But worst of all was the uncertainty.

Everyone seemed to be saying something different. Jill and I were so confused, not knowing who or what to believe.

I felt so drained, so washed out with the shock of it all.

JILL: Whatever else I felt then, I wasn't surprised. This was my third Caesarean. I knew how they worked. The doctors lift the baby out, show it to the parents and say things like, 'Isn't he lovely' or 'What a beautiful baby girl'. But they didn't say anything about Kirsteen. They just whisked her away.

Then when they sent Martin back and didn't bundle the baby up for him to hold as usual I got really suspicious.

But still, I wasn't surprised. For weeks I'd been saying that something was wrong. I'd sensed it.

I just hadn't known what.