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How one small request in your will could save the lives of hundreds of Irish children

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How one small request in your will could save the lives of hundreds of Irish children

Leaving a bequest in your will might mean the difference between life and death for someone else. Ciara Staunton, whose son has had health troubles, tells our reporter why she's backing the My Legacy campaign

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Ciara Staunton with her son five-year-old son Luke. Photo: David Conachy

Ciara Staunton is convinced that her son Luke would not be here today if it wasn't for recent advances in medical care. "If he'd been born 30 years ago, he probably wouldn't have survived," she says. She also believes the ability to deliver first-class medical services is often only made possible by the generosity of donors who leave something in their wills to Irish charities.

Ciara (31) has lived in rural Co Meath since she was a child. After school, she was a nanny with a local family, and loved the work. So it came as no surprise when, following her marriage to mechanic Steve Staunton, she became pregnant with their first child. In July 2011, Luke was born following a "hard" labour, lasting two days and two nights. Soon after, his proud dad gave him his first bottle. But unfortunately, the milk flowed straight out through the infant's nose. Ciara and Steve weren't too concerned, as they thought the baby was still in shock from the difficult birth. So, while mum was wheeled off to the general ward, Luke was taken for an X-ray. Meanwhile, Steve was advised to go home and rest; he'd had an emotional and exhausting couple of days. But soon after, he got a call summoning him back to the hospital.

"Luke was now in ICU because he had a gap in his oesophagus," explains Ciara. A feeding tube was inserted straight away; meanwhile, staff hooked the baby up to oxygen. The next morning, he was taken to Temple Street Children's University Hospital in Dublin. "It only took them 25 minutes to get there from Drogheda," says Ciara. "Steve was following the ambulance. They went so fast, he realised it was much more serious than we'd thought."

Luke was met by a surgical team, who immediately began tests. That evening, an operation, lasting over six hours, was done to repair the gap in his oesophagus. "They kept me informed all the time by phone," says Ciara. "They said things were going well, but slowly."

Unfortunately, more bad news was on the way. During the operation, doctors also discovered that Luke had an anal atresia, and this necessitated fitting him with a colostomy bag. By now Ciara, who was still hospitalised, had had enough. "I couldn't stand lying in bed, not knowing what was going on," she says. So, on the Tuesday morning, having discharged herself, she and Steve rushed to their baby's bedside. Along the way, they got a call from a nurse who told them to "prepare" themselves for what was in store for them when they got to ICU. When they next saw Luke, they didn't even recognise him. "He looked long and scrawny when he was born," Ciara remembers. "But when we saw him in intensive care, he was very swollen. He was on a ventilator, and he had tubes coming out of him everywhere. I was heartbroken."

Surgeon Alan Mortell explained to Ciara and Steve that Luke was suffering from Vacterl association. This is a disorder that can affect several parts of the body (Vacterl is an acronym for vertebral defects, anal atresia, cardiac defects, tracheo-oesophageal fistula, renal anomalies and limb abnormalities). Luke was fortunate, because he only suffered from two of these defects. As far as a spinal problem was concerned, they could only be certain about that once scans could be done when the infant came off the ventilator.

In the meantime, Ciara and Steve had to shuttle between their home in Kilmessan, Co Meath, and Dublin. "We weren't allowed to stay over, because we lived relatively close to the hospital," explains Ciara. "When I wasn't with Luke, I kept my phone in my hand all the time. And I used to call every single hour. The nurses were fantastic. They would take however many calls were thrown at them, and they'd never complain."

Ciara says it was an extraordinarily tense time for her and Steve, but they were greatly comforted by the honesty and skill of Mr Mortell. "Everything seemed like a blur in those early days," says Ciara. "But he sat us down and explained it all to us. He was always very honest and open with us. He told us what the worst outcomes could be, but he also gave us great hope." The next few days were spent helping little Luke to recover from his serious surgery. Then doctors decided to see if they could get him off the ventilator.

Ciara and Steve were told to wait in the family room for about 15 minutes. When there was still no news half an hour later, they began to panic.

But their very real fears were unfounded. Brave Luke had rallied. He spent another two weeks in the high-dependency unit, and then he was able to go home. In the meantime, a scan had detected no problems in his spine. "That was such great news," says Ciara.

However, once he got home, it was not all plain sailing. Luke required tiny feeds every two hours and was constantly throwing up. "He had terrible reflux, which was caused by the condition," Ciara says. "So, putting on weight was a problem. We were up and down to Temple Street all the time for general check-ups, and to monitor the colostomy bag." A few months later, corrective anal surgery was performed by Mr Mortell. It took almost four hours. However, it would still be some months before the colostomy could be reversed.

Things then went reasonably smoothly, until Luke was two years old, when he suffered a prolapse of the anus, which required more surgery.

Now that he was older, hospitalisation was more traumatic for him. "He was uncomfortable and he didn't want to be in that bed," says Ciara. "He just couldn't understand what was going on." But Luke got through the ordeal, and is now doing really well.

"The oesophagus normalised when he was about 18 months," says Ciara. "However, the bowel is still not quite right; but even that is getting better." At the time of this interview, five-year-old Luke, who is happily enrolled in senior infants at his local school, was full of laughter as he played happily with Zoe, his boisterous, full-of-fun, two-year-old sister.

Meanwhile, Ciara is backing a campaign called My Legacy to encourage people to leave something in their wills to charitable causes such as the children's hospital in Temple Street, which has to raise funds to supplement its budgets. The campaign represents about 70 such Irish charities.

"When your child is so ill, you don't think about those machines keeping him alive," Ciara concludes. "But if it wasn't for the generosity of donors, those same machines might not have been there to save his life."

For more information, see mylegacy.ie

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