

By **ANTONIA HOYLE**

How Britain's bravest little boy bounced back from the brink

AS KATE and David Lewis drove to hospital in July 2014, a heavy silence hung between them — filled with the tacit understanding that their four-year-old son James, sitting in the back seat, would only be coming home if he was given a heart transplant.

At the age of three, James had been diagnosed with an incurable heart condition. His only hope of survival was a new heart.

But after 11 months on the transplant waiting list, his little body was no longer strong enough to cope without constant medical supervision and he needed to be admitted to hospital.

Little did Kate and David know as they drove him to hospital that day that it would be another agonising four months' wait for a new heart.

At one point his heart stopped beating. He recovered, but the 15 months he'd spent waiting for a new heart left him with kidney failure (as a result of insufficient blood supply) and he's on dialysis until he can have a kidney transplant. His mother will be the donor this summer when James's condition has stabilised.

He eventually had his heart transplant in November 2014 and in April last year, after nine months in hospital, was finally allowed home. His road to recovery is not over, but his story is one of triumph in the face of immeasurable odds.

'It's only recently that we've begun to relax,' says Kate.

'James is loving, funny and fiercely independent. It is as if he knows what a narrow escape he had and is determined to make the most of every minute.'

It has been a long, harrowing journey — Good Health first spoke to Kate in June 2014 when James, now six, was one of 32 children nationwide in desperate need of a heart donor and every day brought fresh fears that he would run out of time.

As Good Health has highlighted, there is a chronic shortage of donor organs, and one in five patients dies waiting for a heart.

There is a particular shortage of child organ donations — while 31 per cent of adults are signed up to the donor register, statistics from NHS Blood and Transplant suggest 57 per cent of parents would refuse to donate their child's organs.

James, who has a sister Amelia, 12, and brother, Charles, ten, was a much longed-for third child for Kate and David, 44, a share trader, who live in Winchester, Hants.

He was healthy until the spring of 2013, when he went off his food and his energy levels plummeted.

A scan later revealed restrictive cardiomyopathy (RCM), where the lower chambers of the heart are rigid and can't fill up with blood. Over time the heart loses its ability to pump blood, leading to heart failure.

Without a transplant, doctors said James was unlikely to make his sixth birthday. He was put on the transplant list in August 2013, and had hospital visits every six weeks.

THEN in July, 2014, James's consultant at Southampton General Hospital said he should be put on milrinone, a drug that relaxes blood vessels so more blood can be pumped from the heart.

It is administered intravenously, meaning James would have to remain in the cardiac unit.

'Deep down I knew he wouldn't be leaving hospital unless he had a new heart,' says Kate.

'But it had also reached the point where we were so worried that it was a relief he would be surrounded by people who could help him.'

Kate, who gave up her job as a history supply teacher when James was diagnosed, spent all day with her son, while David sat by his bedside all night.

Without a donor, one option was to put James on a 'Berlin heart' — a blood-pumping machine that can keep a child alive while awaiting an organ transplant.

But there is a waiting list and none was available. 'By September James couldn't even get out of bed,' says David. At the end of that month, James's body was so weak that

Time was running out for James to find the new heart he so desperately needed. Just look at him now!

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doctors decided he needed to be in a hospital that could perform a heart transplant as soon as an organ became available.

There are only two such centres that perform heart transplants on children in the UK. Great Ormond Street, in London, was full, so James was flown to Newcastle and the high-dependency unit of The Freeman Hospital.

Kate and David were given a room at the hospital — Amelia and Charles boarded at school and were looked after by relatives, flying to Newcastle most weekends.

'We wanted to keep life as normal as possible,' says Kate.

Three weeks after James's arrival at The Freeman Hospital, he had a cardiac arrest. His desperately weak heart stopped beating.

'It happened in the early hours and James was resuscitated before I got to him. I felt so helpless,' says Kate.

The family was told that without mechanical support James's heart would not survive. He had surgery to fit two 'pumps' that aid the heart by carrying blood out of the lower chambers into the blood vessels.

'Surgeons said James's heart was as hard as stone because the blood wasn't pumping through it,' says Kate.

The rest of his body was failing, too. His lungs, deprived of an adequate blood supply, struggled to function, as did his kidneys. He was put on a ventilator and given continuous dialysis to flush out waste products.

He was also heavily sedated. 'He was attached to too many tubes to cuddle and couldn't speak,' says Kate. 'All I could do was tell him I loved him and read to him.'

'I tried to stay strong in front of the family, but it was so upsetting that sometimes I'd have to leave the hospital to cry alone.'

Unfortunately, the two pumps didn't work efficiently together and James's heart became even weaker. Kate and David had been told there

was little else that could be done for their son when one evening in November 2014 a donor heart materialised.

'I'd prayed endlessly for a new heart and felt my prayers had been answered,' says Kate.

But there were complications. 'The donor heart belonged to someone with a different blood type, which increased the chance of James's body rejecting it,' says Kate.

'And our excitement was muted with fear that James was no longer strong enough to survive the operation. But he was so ill this was his best chance.'

KATE and David knew only that the donor heart had belonged to a teenager. 'I burst into tears as soon as the doctor revealed the news,' says David. 'For their family to make the decision to donate was indescribably brave.'

'As Kate and I walked down the corridor to surgery with James's medical team, my legs felt weak.'

Following the operation, James's chest was kept open and his body attached to a heart bypass machine for a week to help his new heart adapt. Meanwhile, tests revealed he'd suffered two strokes caused by blood clots during surgery.

But slowly, he showed signs of improvement. 'After three weeks he squeezed my hand and his eyes started to focus on us,' says David. 'It became clear he wasn't brain damaged and the colour slowly returned to his face.'

At the end of January last year, he was transferred to the paediatric intensive care unit at Southampton General. The following month he was moved to the hospital's renal unit and weaned off sedatives — it was during a visit by his siblings that



Picture: ROSIE MILLS

The little boy in a race against time to find a new heart



Fresh hope: James enjoying his new-found freedom. Inset: James and Kate in the Mail in 2014

will have a bag of liquid nutrients delivered via his feeding tube every night.

But nothing has stopped him jumping on his trampoline or playing his favourite pirate games — things he could never have dreamt of doing when he was ill.

Kate has written to his donor's family via the hospital's transplant liaison officer. 'I was desperate to thank them and one day would love them to meet James if they get in touch,' says Kate.

She still lays her hand on her son's chest when he is asleep to feel his heart beat, but these days it is more in wonder at what has happened than fear it will stop.

She knows that James's future is uncertain — the average transplanted heart lasts for 15 to 20 years, though it may be possible to have a second transplant.

Kate says: 'Every minute we have with him is a blessing.'

HOW YOU CAN HELP

■ TO JOIN the NHS Organ Donor Register, go to organdonation.nhs.uk or call 0300 123 23 23.