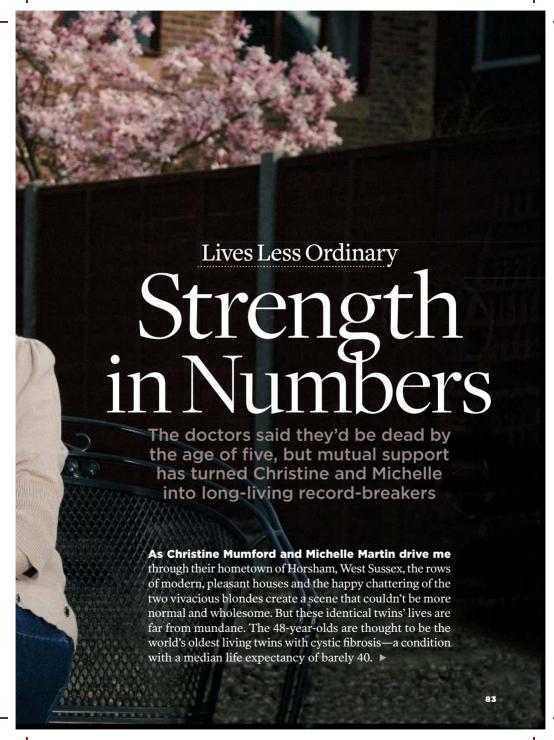


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■ I first met them on a rainy day last September. I'd recently interviewed Jenny Agutter, the patron of the Cystic Fibrosis (CF) Trust and she'd said to me, "You simply have to meet them. They're inspirational."

Then, as now, they collected me from the railway station and we went to a country inn to discuss the possibility of a future interview. But this second visit

"We are extra close because we have this illness that no

one else seemed to understand for such a long time"

is about to become more poignant. Michelle feels too weak for the pub and, during the short journey to her sister's house, she drops the bombshell: "I'm sorry we haven't been in touch for a while. I've been in hospital a lot. I'm afraid they can't do anything more for me. I just have to make the most of every day..."

The news upsets me, and yet the

chatty, funny enthusiasm of these two women, whom doctors thought wouldn't live past the age of five, soon makes me feel better—just as it's made them feel better all their lives.

The twins were born at Romford Old Church Hospital in 1964, and though Christine seemed fine, Michelle had a blockage in her intestines—a frequent

> sign of cystic fibrosis in newborns. She immediately had to have part of her bowel removed. "Very attractive; we call her semi-colon," snorts Christine. Then, a few weeks later, Christine also developed

digestive problems. Tests revealed that she, too, had the condition.

Cystic fibrosis is a mutation of the gene that regulates production of the protective mucus that surrounds our internal organs. Sufferers produce too much, and it gradually clogs up their organs, particularly the lungs and pancreas, causing breathing and digestive problems. The

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A life shared: (from left) aged four months with their parents and brother Nigel; three years later, at home in Upminster, Essex; aged 11 on the beach in Croyde Bay, Devon, where they spent many summer holidays; and celebrating their 21st birthdays in 1985

sticky, moist mucus is also a fertile breeding ground for bacteria, and lung infection is a frequent cause of death for CF patients.

"And we're salty!" adds Christine, explaining that the mutation also creates excess sweating. "In the summer, when my ten-year-old [adopted] daughter kisses me, she always says, 'Ugh! Mummy!' When we were kids, dogs constantly licked our legs. If we go somewhere hot we have to take tablets, because we get dehydrated and can become ill."

Throughout their adult lives, the twins

have had to put up with a constant round of infections, being connected to a bottle to breathe pure oxygen for between an hour and the 24 hours a day Michelle currently endures, and a quite staggering number of pills. "I need 48 different medications each day now," says Michelle, passing me a double-sided sheet of A4 that lists them all next to the precise time of day they must be taken.

When the twins were born, knowledge and treatment of CF was very limited, with patients rarely making it past their teens. The girls' parents weren't even told to pat them regularly on the back, which became a well-known method to help clear mucus from the lungs.

"We were just given pills for our digestive problems, and we'd have to go to hospital for a check-up every six months," says Christine. "But there were always loads of medical students who'd have to guess what was wrong with us. They'd be staring and prodding, and we hated it."

Their current consultant Tim Ho was amazed when they told him how little help they'd got in their early years—they didn't even go to a specialist CF unit until they were 21—but the twins believe that it's their mutual support

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Wedding bells: Michelle ties the knot with Jeremy on July 22 last year

◄ and togetherness that's kept them going so long.

"We are twins, but we're extra close because we have this illness that no one else seemed to understand for such a long time," says Christine. Both have always made sure that their sister has kept to her treatment and not given in during low moments. "We've known people who are no longer with us because they've lost heart and got into smoking or drugs," she observes. And this support has extended to the sort of incredibly sensitive issues that can leave patients who don't have someone to share them with feeling isolated and humiliated.

"All the digestive enzymes we were taking as kids gave us very upset tummies every day," says Christine. "It was very noisy and smelly, and we were worried about people finding out at school. So we made it our little secret. At lunchtimes, we'd disappear to an annex where

we knew hardly anyone else used the toilet, and one of us would stand guard while the other went. If anyone ever came, we'd have a special warning code. Medication makes that side of things much better now, but we were convinced we'd never find anyone else because of it. Little did we know that men are much worse, particularly after a beer!"

The twins, who both worked in insurance, have grown so close that they've developed almost a sixth sense for each other's emotional and physical state. Very often, Christine will ring Michelle to check that she's OK and find the phone engaged because her twin is trying to phone her. The most dramatic example of this came the day before Michelle's wedding last summer.

"I was in bed in the early hours, and I had an image of Michelle coughing up loads of blood. Jeremy, Michelle's fiancé, phoned, and told me she was coughing

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up blood due to a lung infection. I rushed straight round there.

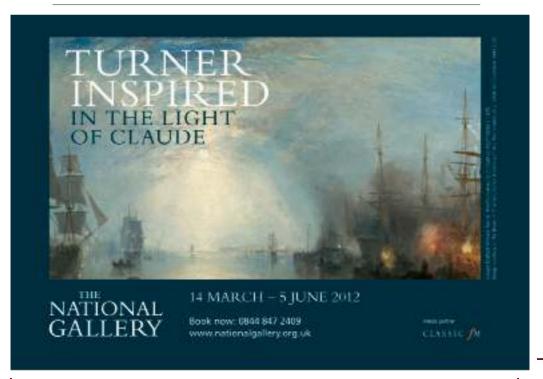
"I went upstairs, and it looked like a film about a serial killer—blood all over the sheets. I cleaned up before her teenage daughter could see anything, then I went downstairs, started on a pile of ironing, and sobbed my eyes out."

But, with her sister already married (to Paul), Michelle was determined not to miss her own big day. So she discharged herself from hospital and—carrying her usual canister of oxygen in a pouch designed to match her dress—was carried up the aisle by her dad.

"We've known our share of hardship," she says, "but we've had lots of happy times, such as adopting our beautiful daughters and having wonderful parents. Yes, the doctors are saying things are bleak for me, but they've said that many times before! We'll see you at our 50th..."

Our interview draws to a close, and the twins drop me back at the station. Birds trill in the warm spring weather; I'm the only passenger waiting for the 4.03pm to London. Suddenly, the peace is shattered by hoots from a car horn. It's the twins driving over the level crossing on their way to pick up their girls from school, waving at me, their tinkling laughter carried on the air as they speed off. "Don't feel sorry for us," their vitality seems to be saying. "Celebrate our achievements."

» Cystic Fibrosis Week runs from April 29 to May 5. For more information, visit cfweek.org.uk



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