PRIMA people



hen my doctor told me it was highly unlikely that I'd ever be able to conceive, I was just 15.

I'm not sure he realised quite how much of an impact his words would have on me, but it was a huge shock. As a child, I'd played with my dolls, secretly wishing they would come alive so I would have my own baby, and I dreamed of meeting someone, getting married and having a family. But from that moment, I truly believed I would never experience motherhood.

Born with cystic fibrosis (CF)—a disease in which the internal organs, especially the lungs, become clogged with thick, sticky mucus, making it hard to breathe-I was used to frequent visits to hospital, hating the smell and sterile green decor of the waiting rooms. But I'd never considered the long-term implications of my illness. At school, it didn't stop me doing sports and most of the time I was able to ignore it.

Although I had a cough when I was growing up, it wasn't severe - more a case of clearing my throat a lot-so it didn't worry me too much. My mum gave me a glimpse of my future, though. Unusually, she had CF as well, and as the disease becomes worse over time, I knew that one day I, too, might experience the coughing fits that would leave her gasping for air. She used to cough until she had no breath left, before taking a huge gulp of air to carry on. Seeing her like that as a child was incredibly frightening, as I worried that I was going to lose her and would anxiously take glasses of water to her to try to help.

I was devastated to discover that the disease could lead to fertility problems, even though my mother had had me despite having the illness (women with CF have thicker cervical mucus than normal, making conception harder). Mum also defied the odds and lived until she was 50 (the average life expectancy for someone with CF is 31), but during her last year, in 1999, her health deteriorated quickly. She developed diabetes – a side effect of CF – and she lost a huge amount of weight. Towards the end, she was very frail, carrying an oxygen tank around the house with her at all times, and her chest would heave up and down as she battled to take in air.

Understandably, everything Mum went through took on a special significance for me and I hated the idea that what I was

witnessing might also be my future. It was a constant reminder of my own mortality.

Although I didn't obsess about the future, something like that is always in the back of your mind, so I made a point of living each day to the full, because you never know how long you will have. And that's the mantra I still live by today.

After being told I was unlikely to ever have babies, you can imagine my joy and surprise when. in 1998, at the age of 27, I discovered I was pregnant. I was living with my boyfriend of five years, Jean-François, then, and he knew about my potential

fertility problems. We weren't using any contraception, but when I was late with my period and bought a home pregnancy test kit, just on the off-chance, I couldn't believe it when the result was positive. I was so shocked that I bought another two kits. Even then, with three positive results, I couldn't allow myself to believe it. I'd programmed myself to accept that I couldn't conceive.

When a doctor confirmed the pregnancy, I was speechless. A mix of emotions washed over me: surprise, delight and wonder, but also fear. Would I be a good mother? Would I be able to cope? Would I get through the pregnancy in one piece? My health had begun to deteriorate-I'd had pneumonia and numerous chest infections - and I was so tired and weak that I worried about how I'd be able to look after a baby. Thankfully, Jean-François had been tested early in our relationship to check whether he was a carrier of the CF gene, and we knew he wasn't. So at least I didn't have to contend with the fear that our baby might be born with the illness. If two carriers of the gene have a baby, the child has a one in four chance of having CF.

The pregnancy was difficult, even so. I was on constant medication, needed blood tests every two weeks and was hospitalised twice for chest infections. I can honestly say it was eight months of sheer terror. I worried constantly that I'd miscarry or that our baby would be born deformed from all



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the medication I was taking. I hated the permanent anxiety, but it was all worth it. Alex was born prematurely at 33 weeks by caesarean section, weighing a tiny 3lb 7oz. When I heard him cry, relief flooded through me. It was the best sound I've ever heard.

Because he couldn't suck properly, Alex was kept in intensive care for six weeks while he grew bigger and stronger. I would sit and watch him in his incubator. overwhelmed with love and disbelief that he was really there, that he was really mine. I still get that feeling even now, ten years on. I look at him when he says something kind or caring

to me and think, "I made you", which is wondrous. I'm in awe of him.

Sadly, our time as a family was shortlived. When Alex was three, I ended my relationship with Jean-François. We'd tried counselling without success, so I summoned the strength to go it alone.

People were amazed that I didn't stay in my comfort zone. I had an easy life-I didn't have to work, Jean-François paid the bills and he loved me to pieces-but I didn't want to "settle". Alex still sees his dad-they spend every other weekend together-while a wonderful mother-son relationship has developed between us.

He was about five when he began asking questions about my illness. When he was a baby, my cough used to startle him and he'd stare at me wide-eyed, but then it became a sound of comfort for him. because he knew I was there. I remember him turning to me once and asking, "Mummy, why are you always coughing? Is there something wrong with you?" I've always been honest with him about my illness, explaining that my lungs aren't healthy. But I don't want to scare him and tell him I might not be around for long.

He's very sweet. He understands when I need to go for a snooze if I get overtired. and he'll rub my back if I'm coughing. He always asks, "What can I do to make you feel better, Mum? How can we fix this?" I always reassure him that I can make myself





Clockwise from far left:
Mandy and Alex have
fun taking cocker
spaniel, Rosie, for walks
in the park; Alex has
always had regular
contact with his dad,
Jean-François; Mandy,
aged four, with her
mum, Jennifer Anne,
who also had CF



feel better myself, though. It's important that I show him I'm in control of the illness, not the other way round.

He does see me coughing, tired and out of breath, which is hard, but like a typical boy, he copes by trying to ignore it. Even so, as he gets older, I think he realises I'm frail and that something might happen to me. Last Christmas, he made a point of keeping all the handwritten gift tags from the presents I gave him. He's never done it

before and when I asked him why, he said he wanted to keep them because they were special, because they were from me. That upset me, because there are some things you just don't have complete control over. I try to maintain my health as best I can, but there's only so much I can do.

I try to keep everything as normal as possible for Alex. A lot of our time

together is spent simply sitting and chatting, or we take our cocker spaniel, Rosie, for walks in the park. One of Alex's favourite things to do is to have me sit with him while he plays World of Warcraft on his computer. He loves explaining what he's

doing and who the different characters are. I really look forward to settling him into bed at night. I read him a story and we talk about the day, what he's learnt or how happy he's feeling.

I'm a qualified psychologist and I run a text-based counselling service (www.text-therapy.co.uk), from home, which means I can have a sleep during the day and manage my CF. I use a nebuliser morning and evening, through which I inhale

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myself as being ill, I won't

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medication into my lungs, and I do daily breathing exercises to help free my lungs of fluid.

I try not to see myself as a victim, but there are some days when I feel very burdened and annoyed that other mothers don't have the worries I have. When I feel like that, I'll give myself a good talking to and remind myself that there are people worse off

than me. Or I'll put on some music for inspiration, female anthems such as Stronger by the Sugababes or Destiny's Child's Survivor.

It's mind over matter a lot of the time. If I think of myself as being ill, I won't be able

to do things, so I tell myself I can do them. I live a normal life—it just takes me longer to do everyday tasks such as shopping or cleaning because I become breathless and have to take breaks. I'm also prone to colds and chest infections and I tend to end up in hospital once or twice a year, when my body is just too

weak to fight an infection itself, so I can have antibiotics administered intravenously,

I worry about how many years I have left and never take life for granted. It may sound clichéd but you appreciate life so much more when you realise how precious it is.

I feel fairly optimistic about the future, as I'm currently taking part in a research trial to find a possible cure for CF through gene therapy. However, as always, it's a question of the charity involved being able to raise sufficient funds.

A cure would be wonderful and would change my whole outlook on life, but I don't count on it. Instead, I just live my life as normally as I can.

I'd love to stick around long enough to see Alex grow up; to see him grow taller than me, go to university, get married. He's my motivation in life and I try to appreciate even the little moments—Alex smiling or laughing or us sharing a joke together. It's those times that I really cherish, because I never take for granted that I will know my son long into his adulthood. The time I have with him now seems even more special because of it.'

■ The Cystic Fibrosis Trust funds research into treating and curing cystic fibrosis. To find out more or make a donation, visit www. cftrust.org.uk.

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