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Like lots of people do, I went to Ibiza after my A levels with a gang of friends. And I was an idiot, as you are at that age – I partied hard and barely slept. We were all run-down when we arrived home, but only I ended up in hospital for six weeks, losing a big chunk of my lung function.

I'd always been aware I had cystic fibrosis (CF) – I was diagnosed at six months old – but it wasn't until Ibiza that I had a realisation about my life expectancy. I couldn't just bounce back in the way my friends did. It shocked me because it was the first time I'd been really ill in an adult ward. I remember looking into other patients' rooms thinking they must have been in car accidents, but when I asked the nurse what was wrong with them, she told me they had CF. I'd never seen people like me at a more advanced stage of the illness. It was a glimpse of my future.

It was then, when I was 18, that a doctor put a number on my life expectancy for the first time – 28. Ten more years. As though I'd never truly understood before, I suddenly thought, 'I've got a terminal illness. I'm going to die.'

CF is the UK's most common genetic disease. One in 25 people are carriers and if both your parents are, there's a one in four chance you'll have it. It's a fault in the gene that means the salt concentration in every cell in your body is wrong. It's hard to maintain a normal weight because your digestive system doesn't absorb fat properly. And the mucus in your lungs is

# HOPE. LOVE. A FUTURE. WE TAKE THEM FOR GRANTED. BUT WHAT IF LIFE FORCED YOU TO TREASURE THE SMALL THINGS?

*What happens to your happy ever after when doctors predict you won't live past 28? Cystic-fibrosis sufferer Rachel Agutter tells her story to Kerry Potter*

much thicker than normal, so you have a bad cough and are prone to chest infections, which causes you to lose lung function. Lungs don't regenerate, so any damage is irreversible. The only option you have is to go on a lung-transplant list when your life expectancy is less than five years and your lung function is 30 per cent. Half of sufferers die before a transplant because there aren't enough donors.

Throughout my twenties, I had the age of 28 imprinted on my brain. As a result, I spent those years clubbing and staying up all night. I had no interest in long-term relationships. I wanted to have fun and for everyone else to have fun. Luckily, that's what they wanted at the time, too.

There was more to my life, though – working, commuting, paying bills – and

some people would ask (and still do) why I wasn't just living it up on a beach in Goa. It crossed my mind at times. But if I were, I'd be somebody who's not dealing with things very well. What would I do? Come back home when I'm at death's door? I've had my whole life to get used to the idea of being ill. I've always had a daily regime of physio to clear my lungs, used nebulisers and taken pills – it may sound awful to you, but anything can become normal with the passage of time. I've always had the same aspirations as my friends: getting my own place, having a career. I like that sort of life. I am probably an inherently sensible person. I worry about the future of the planet. I have savings. I do want to live life to the full – but it's normality that I aspire to. ➤

So after my post-Ibiza wobble, I went off to university and back to regular life. I enjoyed being a student and a year of travelling afterwards. It wasn't until I got my first job that I realised my limitations. I worked as a PA to a team of brokers in the City – it was long hours, hard work and a lengthy commute. I kept getting ill and my bosses would call me in hospital to find out when I was coming back. I think they just thought I was lazy and eventually I had to resign. I was so scared I wouldn't ever find a job again – who would want to employ me? My doctor told me to consider working part-time and I was devastated, I thought I'd never be able to be successful if I couldn't put in the hours to achieve it. I was 22 and all my friends' careers were taking off. We were at that age where people start to be defined by their work and I felt defined by having none.

I found a part-time receptionist job that wasn't too demanding. It gave me enough money to move out from the family home in Surrey to London with friends. I could focus on getting my health back on track and I had time to learn new skills. I ended up training as a magazine picture editor, which I still do on a freelance basis. Everything always comes back to quality of life – I can't imagine doing something I hate, nine to five, because it's such a large proportion of your life – anyone's life, let alone mine. Rather than curtailing my ambition, CF has made me more driven and spurred me on to find a career that works for me and makes me happy.

But then, of course, as I get older, everyone is starting to settle down – you go from thinking about the next weekend, the next party, to thinking about the next few years of your life. I met my boyfriend, Adam, at a music festival when we were both 26. When you have CF and a man pursues you, you know he must genuinely like you, because he's aware you come with baggage. I found out later he'd researched CF on the internet when he first met me. I felt able to open up to Adam very early on and say, 'Look, I don't know what my future is going to hold.' We've had some quite intense times – I had a period when I kept collapsing for no reason and I'd end up in hospital. He

makes sure I take all my medicine and that I eat enough – he's turned into an amazing cook. As for the rest, his approach is just to take it one day at a time.

Four years ago, when I got to 28 years old – the age I was suppose to die – and was still fairly well, I thought, 'I'm here, now what do I do?' I had a great boyfriend, a great job – but no real plans for the future. And it coincided with a time when all my friends were starting to get married and have children. I deal with it by having projects year by year. Last year was about Adam and I buying our first house. This year we're doing it up. I don't know about next year yet.

I have been thinking about having children, too, and realise it's highly unlikely I will do it. It would be risky to my health, but also I wonder if it's selfish to have a child when you know full well you probably won't see them into their teenage years. Adam is very laid-back about it and thinks we should do whatever will make me happy. When you reach your thirties, everyone is planning the next 10 or 20 years and I can't do that. I try not to let myself get resentful – if I did, I'd enter into a horrible place. There are times, though, when you think the whole thing is really unfair. My brain is pretty good at blocking things, but sometimes something will set me off. It happened a few months back. I was having lunch with my oldest friends – I've known them since I was four – when one of them announced she was pregnant. Then another said, 'Oh, so am I!' That was a real tipping point for me. I held it together for the day, but when I got home, I cried to Adam for hours. Other people are so lucky to be able to do things without thinking about it. Every life decision I make has a million other factors. But I need to make sure I remain close to my friends and don't turn into a bitter woman. I don't want to be that person. I worry, though, as everyone gradually moves over to 'the other side', will I be stuck in this Peter Pan moment?

I'm not obsessed with numbers any more – 28 was the big one and it didn't happen, so I realise now that you really don't know. I could get ill tomorrow, never bounce back and die. Or I could gradually get more ill, month by month. It's difficult to get used to the fact that it's completely unpredictable. I'm now 32 and my lung function is 45 per cent. My doctors told me last year I might be able to make it to

*'When I got to 28 – the AGE I was supposed to die – and was still fairly WELL, I thought, "Now what?"'*

40 years old if I'm really committed to my treatments. That motivates me to work hard, but it's difficult when I do everything I can and my lung function still goes down. It's beyond my control.

It would be nice to say the person I am has nothing to do with CF, but of course it has everything to do with it. It's shaped my personality in all sorts of ways. It makes me tolerant – I'm good at putting things into perspective. But when friends moan about small things – say, if their boss is being annoying – I accept that everything is relative. If I was in their position, I'd feel the same. I have to take a step back, otherwise I'd fall out with everybody. I know that if I didn't have this illness, I'd soon find something else to worry about.

Recently, my parents retired and moved permanently to their holiday home in the Cotswolds. They are having so much fun, going away, spending time with their friends. It must be great at that stage in your life. For the first time, I've realised I'm not going to be like my parents. I'm never going to be in my sixties. It makes me feel sad. But, at the same time, I think, 'You never know.' I've always had this little kernel of hope that there might be a cure. I truly believe that children born with CF now will see a cure in their lifetime. That brings me some comfort – as well as making me a little jealous that I will probably miss it. ■

*For more about cystic fibrosis, visit [cfrtrust.org.uk](http://cfrtrust.org.uk)*