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YOU'RE JUST ONE HOUR AWAY FROM BEING LESS STRESSED

Jools Oliver
Jamie would do anything to have a boy
‘What a LIFE-THREATENING ILLNESS taught me about living’

I’ve never been one for thinking about the future. In fact, I can’t. I have a heart condition and people who have it usually die before they reach middle age. My doctors have always advised me to live my life to the full and I’m happy to say I have. People call me brave, but I know I’m not. I just do what anyone would. Weirdly, I feel blessed, because my outlook is so different to many people’s – I don’t get bogged down by the details. I know that if your house isn’t big enough, or you haven’t got the right car, it doesn’t matter. I’ve never consciously thought about this before, but I suppose this is my life philosophy.

Be honest with people

When I met my husband, Chris, 12 years ago, we were both working in pressurised jobs in the City, he as a trader, me as a broker. I knew quite quickly that Chris was going to be important to me and, after just a few weeks, I blurted out, ‘Look, I’ve got heart disease and I probably won’t live beyond 50.’ I told him we’d never be able to have children and that I might get sicker and sicker. He simply said, ‘I’ve chosen you and, if that’s how it is, I’ll take you as you are.’ We were married five years later and, since then, I have been about as sick as it’s possible to be. I have felt like a real burden at times, but Chris has always made me laugh and kept me fighting.

Focus on what you can do, not what you can’t

I’ve known about my condition (acute hypertrophic cardiomyopathy), since I was nine years old. When I was diagnosed, I didn’t understand what it meant. But I do remember my mum crying all the way home. She did understand – the illness is genetic and she had it, too. My mum was tall and blonde and feisty and, right up until she died, 10 years ago, aged 50, I never realised quite how sick she was. In hindsight, I think she protected me from the reality of her illness – and mine.

After the diagnosis, I carried on playing netball and doing all the things a nine year old does, but I’d often feel like an elephant was sitting on my chest and I couldn’t breathe. My mum sent a letter to school, saying if I didn’t want to do PE, not to force me. I didn’t feel deprived – I simply became really bookish, concentrating on my schoolwork and exams.

My wake-up call came just after graduating from university in 1989. I was in a job...
I hadn’t worked physically within a week, it really tipped me over the edge. Stroke affects the brain and I was terrified that would be taken away from me, as well.

Forgive yourself the downtimes
My consultant, Dr Perry Elliott, told me that my heart had started fluttering and the blood had pooled in my heart and clotted, causing circulation to my brain to stop momentarily. He gave me a gruelling drug that made my skin turn grey and paper-thin. Finally, I could no longer pretend I didn’t have a life-threatening illness. I’d like to say I handled it, but I didn’t. I became frustrated and depressed, thinking, ‘Why me?’ But something changed in me when a nurse said, ‘Look, just stop criticising yourself – sometimes, you just have to let yourself feel bad.’

When the brave face fails, let it
I’ve spent a large part of my adult life faking to the world that I’m not in pain or scared. I had a pacemaker put in and went on stronger drugs but, by the summer of 2005, my quality of life had dwindled so much, I didn’t have the energy to pretend. I was weak and gaunt, I had no colour in my eyes, no energy or brain power. My heartbeat had gone down to 36 beats a minute and I didn’t have enough oxygen going round my body. I hadn’t worked for two years. Chris would leave in the mornings and say, ‘Try to have a shower.’ Sometimes, I couldn’t get out of bed.

Dr Elliott sat Chris and me down, and told us my only option was a heart transplant. ‘Without one, you probably won’t live more than a year,’ he said. I was so stunned, I couldn’t speak. Dr Elliott explained that it would mean more drugs, more side effects and a one in five chance of my body rejecting the heart. He told me my face would swell up, like a balloon, from steroids, and other drugs carried the risks of skin cancer and kidney failure. If someone asked you to gamble your money at those odds, you probably wouldn’t but, when it’s your life, it was a no-brainer; Chris and I had been married just five years and I wasn’t ready to leave him. Before making the decision, Chris and I declared an embargo on discussing it.

Count your blessings (especially when things are bleak)
Even at my sickest, I couldn’t stop thinking how lucky I was. I had an incredible, positive husband. My friends were supportive and, although I couldn’t work, financially I was fine. Some people have to struggle with ill health and money problems and have no-one. I wasn’t afraid of dying, only for Chris’ sake.

Ignore the What Ifs
I was put on the waiting list at Papworth Hospital at the end of 2005. It’s awful – you’re effectively waiting for someone else to die. But I never once thought I wouldn’t get a heart. Six months after going on the transplant list, we were at dinner with an old university friend and her partner. I usually avoid alcohol, because it taxes my liver and kidneys, but, that night, I thought, ‘Sod it, I’m sick of being ill.’ Just as we were opening our second bottle of wine, my mobile rang and it was Papworth, saying they had a heart for me. I got there at midnight and, by 6am, I was about to go into theatre. We’re Catholic, so a priest came and did a blessing.

Tell your loved ones how you feel
Just before I went under, I made a speech to Chris that I’d prepared, in case it was the last thing I ever said to him. I told him his face was the last thing I wanted to see, before going under, and the first thing I wanted to see, when coming round. He kissed me and simply said, ‘I love you.’

I woke up in the ward, feeling fantastic. I knew it was the morphine, but I sat up and stared at my hands and feet. They were pink! I was warm, where all my life I’d been cold from having terrible circulation. All I could hear – literally – was the boom, boom, boom of my normal, beating heart, a sound so foreign that it kept me awake for the first few nights.

That high was short-lived. A week later, my body rejected the new heart, and I almost died. I had intravenous steroids for three days, with side effects that made me feel like I was going crazy. But, I came through and, after three weeks in hospital, I went home. I had to take 18 different pills every couple of hours, but I slowly began to feel normal again. All the emails and letters from friends and family were a huge source of strength. Ordinarily, people never say how they feel about you, but it really is incredible to be told.

Smell the roses (and look at the rainbows)
I remember the moment I knew everything would be okay. It was soon after leaving hospital, and I went for a walk with my friend, Corinne, on Wimbledon Common. She said, ‘Look at you now’, because I was walking the dog and couldn’t have done that a few weeks before. Then we saw the most enormous rainbow. I said, ‘It’s a sign’, and we both cried our eyes out!

Now, it’s so exciting to be sporty. As well as walking, I began swimming lessons just after the operation. And, this month, I’ll be taking part in the British Transplant Games 2008, doing a 50m freestyle swim and a 5k walk. I’m doing it for Papworth Hospital, which is particularly special – they did, after all, save my life.

I still don’t plan much but, although no-one knows whether I’ll live five years or 25, I now occasionally let myself imagine what it might be like to have a long life. And I have a terrible urge to go dancing all night long. Just because I can.