

Amy Deane - From Illness to Recovery

In the summer of 2003 – that glorious, hot, Mediterranean-style summer when planning a barbecue didn't mean keeping the oven warm in case it rained – I fell suddenly and unexpectedly very ill. What started out as something that looked like a passing bug, turned out 8 weeks later to be acute critical ulcerative colitis.

I had gone from being healthy and energetic, reasonably fit, and someone who was careful about diet, to finding my health spiralling out of control and my weight plummeting. Eventually, after the hottest bank holiday anyone could remember, my doctors decided that drastic action had to be taken and I was faced with the probability of a serious operation. The sudden explanations of what I would be likely to be faced with after the operation were very upsetting and frightening and I could feel a rising panic. I asked my doctor to give me one positive thing to focus on. He paused and said that usually they are able to successfully treat my condition with drugs. I stopped him before he could utter the "but..." that was hovering on his lips and spent the following several hours as I waited for the final verdict, meditating solely on this one positive piece of information. At some point during this time I slipped into a feeling of immense calm and when the news finally came that the operation was not only imperative, but urgent, I wasn't frightened any more. I wish I could have passed on that calm to my terrified father who had no choice but to hand me over to the surgeon and trust that he would do his best for me.

The following morning, I woke up in hospital with my concerned brother beside me, with no colon and horror of horrors, an ileostomy bag. The emergency operation I'd had the night before had saved my life – "Another 24 hours and we'd have lost you" the surgeon said. My wonderful, caring, skilful surgeon, who if I'm honest has frankly God-like status in my world. It's hardly any wonder that doctors are so revered. The truth is, I would not be here if it weren't for The Great Getzen!

So while everyone else was enjoying the hot weather, replacing Sunday roasts with barbecued chicken drumsticks and sausages, I was lying in hospital still suffering with sickness, coming to terms with my strange new plumbing system and praying for rain that would cool things down.

During those long weeks, I could do nothing but live hour by hour, day by day, trying to be as patient as possible about my slow recovery and not think too deeply or emotionally about the shocking situation I was in. The wound from my operation wouldn't heal properly due to the low levels of protein in my system, eating, frankly made me feel sick, I'd lost 2_ stones in weight and my hair started falling out in fistfuls. I stopped looking at myself in the mirror because I was so horrified at what I saw staring back at me. I looked like I'd just been released from a concentration camp.

I was given protein drinks four times a day, but never got through them all - they were disgusting and made me feel sick again. Determined though I was to get better quickly, I just couldn't get those drinks down me! Eventually, I gave up and when my appetite returned, I took to snacking on cashew nuts all day and drinking full cream milk.

The doctors and nurses were fantastic. Not only did they clean up after me when I was ill, they taught me how to look after my new appendage, treated my wounds with care and encouragement, helped me wash myself, and maybe most importantly, made me laugh. On one particular occasion when I couldn't keep the tears from coming, one of my doctors pulled the curtains round my bed and sat with me for a while. I will be eternally grateful to her for just being there that day. We are now friends and she continues to be an inspiration to me.

Only family and a couple of close friends were allowed to visit, partly because visits of more than 2 people were exhausting, but also because I really didn't want anyone to see me looking so very ill. But I received many many messages of love and support - over 70 cards in all, and all of which I've kept. I'm convinced that all that love played an important part in my recovery.

By the time I was allowed home at the beginning of September, the glorious summer was almost over. Although I was well enough to go home, I was so weak from being ill and almost immobile for so long that I had to be helped up the steps to my

house. For the first two weeks I was looked after first by my best friend, Kirsty, who travelled down from Scotland to stay for a week, then my incredibly patient boyfriend who also took time off work to allow me to be in my own house, which was very important to me.

Having been used to being a very independent person, it was very hard to accept that I simply had to ask for help to do things. Even chopping an onion was hard work, and getting saucepans out of a cupboard impossible, so friends and family brought meals round for me. I remember one particular occasion during my first week at home, dropping something on the floor in the kitchen, crouching down to pick it up and not being able to get up again! The muscles in my legs simply wouldn't lift me, my arms were also too weak to pull me up and there I was stuck sitting on the kitchen floor! My immediate concern was that Kirsty would come home from the shops and tell me off! Eventually I managed to shuffle over to the step by the door and haul myself back onto my feet - a lesson learnt, I had a long way to go.

What I did learn during that time, was to let go and let people help. I learnt that I'm not alone and I didn't have to prove my independence, to myself or to anyone else. My mum would come round and change the sheets for me, my sister in law gave me weekly massages, neighbours offered to do my shopping and my dad visited me every day and drove me to any appointments. I also had daily visits from the district nurses in those first weeks, and they too were just amazing. So kind, so caring, and would often stay for a chat if I was a bit down.

I was so desperate to put on weight at that time, I would start the day with two Alpen bars - before breakfast - and continued eating nuts, always having a bowl to dip into somewhere nearby. I was the envy of my friends because I could eat anything - chocolate eclairs or doughnuts with a cup of tea was the norm!

Everything else was still hard work though, I gradually built up the distance I could walk from the house without my legs going to jelly, I had a seat in the shower and a low stool in the kitchen so that I could get things out of the cupboards and the oven.

After a few weeks of lying on the sofa reading and dozing much of the time, I wanted something else to do and started making cards. I'd always loved making things when I was younger and it seemed like an opportunity, as well as acknowledging my own advice to my coaching clients in the past, to 'explore your creative side'. I enjoyed making the cards so much that I eventually started selling them, to a couple of local shops, some friends, and my district nurses! I also made all my own Christmas cards that year, which seemed fitting, after all the cards I'd received in hospital.

During all this time, I also had to get used to having the ileostomy bag. In many ways I was so lucky. Before the operation, it was uncertain whether I was suffering from Crohns or ulcerative colitis, and I was told by my stoma nurse that I could celebrate that it wasn't Crohns, which affects the whole of the digestive system and is therefore treatable but not curable. The removal of my colon had removed the colitis, which had nowhere to return to, and the ileostomy was reversible. I hated the bag, I have to say that, and I know that many people have to live with it for the rest of their lives. I fully respect the way people deal with that, and know that had I needed to, I would have found a way of dealing with it too, but I am immensely relieved that I didn't have to. Apparently, in the first days after the operation, I refused to speak to the stoma nurse, I suppose in some way trying to resist the reality of it. But once I was ready, she was of course fantastic, like all the other health professionals I came across during the period of my illness.

Being ill was one thing, but having the ileostomy bag, for me was the final stripping of my dignity. I felt deeply unattractive as a woman and quite disgusting as a person. Living on my own, the bag and I developed a mutual respect and understanding, but being with other people was another thing entirely. The noises that I had no control over were sometimes mortifying and I was deeply conscious of whether it was noticeable from the bulge in my clothing. I did get over most of this, and by March, I was out on my bike and pretty much doing what I wanted.

But my relationship with my boyfriend suffered irreparably. This was entirely down to the way I felt about myself. We hadn't been together that long and I didn't want him anywhere near me, no intimate physical contact, no kissing that would become a cuddle and create contact with 'the bag', nevermind the fact that I also had this awful gaping scar where my smooth tummy

used to be. I hated my body and there was no way anyone was getting anywhere near it. Despite all his loving care and devotion, our relationship ended.

During my recovery, putting on weight and starting to live my life again, always in the future was the shining goal of the reversal operation. The day finally arrived at the beginning of May, 11 months after I'd first fallen ill. It was a much bigger operation than I'd anticipated, but the Great Gatzon looked after me. He even kept his promise to tidy up my wide scar and re-centre my tummy button, which had meandered off to one side slightly during my healing. Being back in hospital was grim, and there were a few challenges to be met with the pain treatment not working, then becoming dehydrated, when I thought it had all gone horribly wrong and maybe I wasn't going to make it. I still had an ileostomy bag, this one slightly different, and temporary. May to August was a nightmare time as I went back to being incapacitated again and the new bag was very unpredictable. I didn't think I had any more dignity left to lose, but what little I had was definitely challenged during that time! Out of self-preservation, I chose to stay at home even more, after several experimental and excruciatingly embarrassing incidents.

I had low days, but somehow managed to keep my head just above water, refusing to drown in self pity and let this get the better of me. I was still here, after all! I did and do have so much to be thankful for. But you can overdo the whole 'instinct for survival' theory. I know full well from past experience that burying emotion doesn't work, it will catch up with you in the end, which is, I believe, how I ended up ill in the first place, by burying my grief for 25 years. I don't want to hide from anything anymore.

In August 2004, I had my final small operation to reconnect my new plumbing system. The incredible reproductive work my surgeon had done was put to the test. Immediately after the operation, I was told that I couldn't start eating again until I'd passed wind - a function not performed by this part of my body for a year! When the moment arrived, I walked out of the bathroom and called to my fellow patients in my bay on the ward, "Ladies! I have an announcement to make....!"

Nothing's ever straightforward though, and I'd got used to not expecting miracles immediately. The first few weeks were very uncomfortable as my body was re-employed and tested. The most devastating thing was that I was desperate to celebrate but every glass of wine caused terrible problems! Eventually this all settled down and on 12 September 2004, I celebrated my birthday with my family and close friends. It was a good day. A very good day.

It may be a cliché, but this isn't a dress rehearsal – and I very nearly got bumped from the main performance! Coming out of a period of serious illness and gradually no longer needing all the care that I'd relied on in that time, I felt like a prisoner released from captivity, standing outside the prison gates, suitcase in hand, looking at a whole world of choice, thinking, "Now what?" I had experienced just how fragile and unpredictable life can be, and I fully intend to make the most of the rest of it and use what I have learnt to help others do the same.