

# Chapter 5

## My Story... so far

*In Sussex, Anon*

I trained as a nurse in London, wearing lovely uniforms and being at the forefront of medicine. During my second year I opted for a placement in a large psychiatric hospital in Surrey. It was huge, with its own farm and church, and set in beautiful surroundings. As a student I was sent to various units including locked wards, an ECT<sup>1</sup> suite and psycho-geriatric wards. Patients were just people who got in the way of the running of the place and I can remember the space, light and air, but the care was minimal. Patients were given clothes to wear: women had a clean apron weekly and clean dress every fortnight; the bread was buttered, the tea sugared and institutional living was the norm. I hated this type of control of people, and the lack of personal care. Everything was suited to the running of the hospital and nothing to the individual patient; it all seemed terribly wrong.

When my second child was born, I remember thinking something was wrong. He cried a great deal and hardly slept. A visit to the local paediatrician resulted in him being quickly prescribed Largactil and me being told I stimulated him too much. All I could think of was a night's sleep so I gave him the medicine, but for a short time only as I thought his liver would suffer. I remember waking up when he was about four or five years old, listening to him talking to his farm animals and soldiers and wondering how he could not be tired, but somehow he just kept awake for days and days. For me this was an overwhelming time as I also had a little girl; those levels of exhaustion have stayed with me until now.

James had excellent gross motor skills, so he could ride a bicycle, swim, run and jump at a very young age. He required a lot of input and I became adept at throwing and catching cricket balls, usually with the supper cooking wildly on the stove and me rescuing the meal just in time. I was aware that his concentration was not good, except for sports, so as a family we became loyal supporters of his sporting interests. He will say he had a happy childhood, but always at the back of my mind I knew something was wrong. However, without knowledge or any idea of where to get it, I felt helpless. To the outside

<sup>1</sup> Electroconvulsive Therapy

world he was a blonde, attractive little boy with the ability to read the flight of a ball; so what was the matter with me, and who could I discuss it with?

## **First concerns**

My first real concern was when I was told by his prep school teacher that he could not be found. A search was made and he was eventually found gazing out on the cricket field by himself, having left a lesson. So, an 8-year-old stands and stares; I started seriously thinking something was not right.

As his teenage years approached I felt very uneasy and successfully persuaded James to visit his GP to discuss mood swings and anxiety levels, but all in vain: the kindly GP called me to placate and smooth the path and said how well-adjusted and charming he was and what a good cricketer. Needless to say, this did not help and left me feeling very bewildered.

Back pain was a problem, together with unexplained behaviours and isolation from the family. I felt compelled to keep him busy and involved with activities; he ate, drank and slept cricket but, on a move to Sussex, became more isolated. Two trips were undertaken to Barbados to play cricket, and I was worried that if he got into trouble he would be incarcerated, but on his return he decided to visit his GP about the increase in back pain. The orthopaedic consultant decided that unless James had a piece of bone taken from his hip and grafted onto his spine he would be in a wheelchair very soon as the nick in his vertebrae would pierce his spinal cord, leaving him unable to walk. The surgery was brutal and he was in a full body plaster for weeks, unable to move or shower and living on painkillers; for some reason I was so involved with the physical aspect, I actually forgot about his mental health. After a long time James was sent back to the orthopaedic consultant to find that everything had broken down and there was an urgent need for another spinal fusion operation.

He was admitted and his spine was hooked up with wires and fused together. I remember thinking that this time he was psychologically scarred and that his sporting days were over. The days and weeks that followed were traumatic, learning to walk on a huge amount of analgesia and accepting that this was how it would be now. For months I was worried about what he would do – sport had been his life, and now it had been taken away. I hit on the idea of applying to a local drama group with the thought that perhaps he could give

out programmes. To placate me he agreed to go, and returned from the first meeting full of enthusiasm for acting. He auditioned and was given a lead part. I remember thinking how happy and untroubled he looked. For weeks he attended rehearsals, and I was booked every day to hear lines. We saw the play and were amazed by how he carried a ladder on stage and pretended to get into the girlfriend's bedroom. As it was a farce, he made a meal of it and was terribly funny. On stage, James seemed in control, and became the person he was acting.

## **Mental health crises**

One fateful Saturday, as the Nat West cricket final was on the TV, James was found curled up in the foetal position. I was not his mother, his sister was not his sister and his level of confused thinking was alarming. Our GP arrived and James was persuaded to go to hospital as a voluntary patient. He took medication and, after a very long time, was discharged. He had strange beliefs and sometimes talked about them. This followed numerous admissions and a degree of aggressive behaviour with thoughts of persecution and being tortured. He believed that I had been a prostitute and was in collusion with mental health staff.

He eventually took himself off to drama school. After a while he went to a drama college, and although he enjoyed the experience at first, after a couple of terms he came home for good. He went through a revolving door period of taking the medications, long relapse, detained under the Mental Health Act, treated for months and then discharged; each time the fear and dread of the unknown increased.

He wanted to get back to the theatre. He was making nuisance phone calls to the older lady whom he believed he'd had an affair with – re-occurring thoughts from his very first admission. The police were involved and I knew he was just on the edge of normality. He continued to have admissions – sometimes in Psychiatric Intensive Units, where he was completely locked up. His beliefs returned so powerfully that he thought I was involved in prostitution or had been abused, and also strongly believed I was responsible for his incarceration. He was convinced he had been a prisoner and could describe being tortured. The list could go on and on. He thought he was linked to the Pentagon and still the lady, whom he had only spoken two words to, was his long-time lover.

On one occasion when James was an inpatient, I was contacted by the ward to say he had been attacked and taken to theatre at the local hospital as his arm was broken. On his return from surgery he was left alone on a trolley and the attacker hit him around the head. After a long time and many meetings I sued the hospital for negligence, and James was awarded some compensation. I felt relief that no one else should ever have to witness or suffer what he had, and hoped that the Trust would make psychiatric intensive care a priority and offer local provision.

## **A terrible day**

In 1999, the day after Boxing Day, I went shopping in London with my daughter while my husband and James went to play golf. It was a terrible, wet day. James met us off the train in the evening looking ashen; we were laughing about our bargains and swinging our shopping bags. We were told that my husband had collapsed on the golf course. Apparently the helicopter had been unable to land, so James had had to run to a nearby house to call the ambulance and try to resuscitate him. For all of us this was a terrible time; although the psychiatric team gave us support, I knew it was just a matter of time before James had another relapse.

When I remember my husband it is for his great kindness, sense of humour and complete love for me and his children. He supported James with all his enthusiasm and encouragement, but found the lack of logic and the behaviour patterns difficult to grasp. He was very protective of me, and tried to shield me from the awfulness of relapse. We had a very busy life and, at times, planning for the future was overwhelming. When he died so suddenly my world changed overnight: I was now the head of the family, with the knowledge that I had the burden of James.

My daughter was seriously thinking about not having children. Although, as far as we know, James is the first person in the family to have a mental illness, she was acutely aware of the devastating effects it can have on a family. Elisabeth became very protective of me, and although she worked in London she came home every weekend to be with me. We just got on with it the best we could, with the sure knowledge that Dennis would never have chosen to leave us. The mental health team were prompt to visit James, but within a year he was readmitted and the revolving door started again. I managed situations knowing that I was my own tap root now and had to make decisions on my own; chatting over a cup of tea or coffee was over and I was finally

fully grown-up. I still feel that James was dealt a dreadful blow to have had to witness the sudden death of his father – which to this day I know he has not recovered from. I have been sustained by my faith, and have often felt looked after. During that horrible year of 2000, I was very ill with a perforated colon and peritonitis. I remember lying in the hospital, miles away from home, and feeling that someone was watching over me.

## **Moving forward**

I have always been acutely aware of when James is showing relapse signs. In the early days no one ever paid any attention or listened to me, so every time I spoke to a professional with the explanations, the signs and changes in presentation were ignored. It was as if I counted for nothing and had nothing to contribute to his care or treatment plan. Staff would get very worked up about confidentiality, with little understanding of what I was doing in the background. One of the most frequent signs of relapse was paranoia against me, and even though I was dealing with his financial affairs, paying bills etc., I would not be allowed to be told simple things like decisions made at a ward round. I must say, though, that this attitude has improved; also, the blame culture is much less in evidence and the respect for dignity has improved. More space on the wards with privacy and routines that are less rigid yet have boundaries have made for a calmer, cleaner and healthier environment, and an understanding of spiritual needs has made inpatient care more caring.

James has been an usher at his sister's wedding, travelled to Egypt twice to see her and enjoyed riding a camel around the pyramids. He has helped me enormously with lots of things when well, but I am acutely aware of what he has experienced, seen and heard as a user of mental health services. The consultant psychiatrists have always worked tirelessly to find the right medication (no easy task as he is drug resistant), but in recent years the attitude towards carers and relatives has been so much more enlightened. The assertive outreach team have surpassed themselves, and their positive and persistent attitude has been likened to a 'dog with a bone' approach. I can only be grateful – in fact words cannot convey my admiration and respect for all the team members.

## **Reflections**

Writing a potted history of James has been difficult. However, while I would

never wish this terrible illness on anyone or their family, it has enabled me to meet extraordinary people and have a better understanding and respect for mental health workers. I hope and pray that medicines improve and the media help with stigma, and that we as a nation will continue to support people and carers who experience serious mental illness.

On reflection, my thoughts keep returning to the early concerns and possible neglect of my daughter – not intentional, of course, but I am sure it was the case. My husband's inability to solve the problem or in fact understand illogical thinking and behaviour was also a burden. Relationships with staff members who seemed unable to understand my anxiety and offered throwaway comments did not help, together with other people all being experts' with their strong opinions. My life is about always sorting things out and being aware that a 40-year-old is not a little boy, about how much to discuss with him and not giving him any further anxiety, about holidays and always hoping he would be all right.

The worst things are often coping with the bereavement over what might have been: a job with respect, family and grandchildren, a nice home and independence, friends and neighbours. I am now resolved that this is how it will be – surely we have both been through enough – and that we have to learn to live with this. Many people have it worse, and I tell myself we have our arms and legs and our heads are on, but it has been a struggle.

Finally, I guess that as a small family unit we have been lucky, because we have supported each other. I am not the same person who became a youngish widow. I have done various jobs and a lot of travelling on my own. I have opened my garden with the National Garden Scheme and raised a large amount of money for charity by selling tea and cakes with my children on hand (James washed up all afternoon – for almost 250 people!). I have trained to become a magistrate, started and run a successful business and explored parts of the world that I would never have thought possible to see. It is not all bad. I would say that although James has been seriously ill in ITU (Intensive Treatment Unit) with respiratory failure and then renal failure, and we knew he was near to death, nothing has been as bad as the mental illness. I take comfort from the fact that he knows I will always support him, and in his own way he definitely supports me. When well he is the kindest and most thoughtful person who battles daily, and I admire his tenacity. I suspect he will not make old bones but for the moment he's managing – and, I guess, so am I.