

Chapter 2

Recovery... a strange word for me

In Sussex, Anon

I was advised some twelve years ago that my daughter's most likely diagnosis would be schizophrenia. I read, delved deeply into the internet and asked for information about expected future outcomes for her and how I, as a parent, could or would cope. A year later the consultant confirmed my fears. He informed me, explained the possible future and, with his help, I began my journey towards accepting and therefore starting on my own road of recovery from the shock, disbelief and the mourning of my lovely daughter's future.

In 2004 a new consultant joined our local Trust, took over and turned the diagnosis on its head. Not a psychotic illness but one of a psychological nature, was his opinion... nurture not nature. He implied that my daughter had suffered abuse, had had a bad upbringing and was now suffering from one or all of a number of labels associated with psychological issues: dissociative identity disorder, borderline personality disorder and/or post-traumatic stress disorder. She was hospitalised again and again and filled with test doses of various drugs, but only seemed to become more and more psychotic. He insisted that I should not visit her. She was then admitted by this consultant to a private hospital for the treatment of post-traumatic stress disorder. They diagnosed schizophrenia. She was readmitted to our local Trust, where the consultants refused to acknowledge the diagnosis and refused treatment. I fought to have a second opinion from outside the Trust, away from the very opinionated, arrogant, biased consultant whose dictatorial and wholly wrong diagnosis had caused my daughter and our family so much unnecessary suffering. Not only was my daughter completely 'mad' following two years in his 'care' but I felt beaten, betrayed, unheard and unable to protect my daughter from his and his colleagues' distrust of a parent/carer's care and opinion.

I fought and won; a consultant was sent from a London Trust. He immediately diagnosed my daughter with a psychotic illness and she was admitted to the Bethlem Royal Hospital at the beginning of 2007.

In my opinion, much of recovery – or ‘regain’, as one dictionary defines the word – depends on the wellbeing of the person to whom you are giving care and all the others involved in their care. I had left our local Trust feeling like a beaten dog; I was exhausted, had lost weight and generally felt that no recovery of any sort for either my daughter or myself would ever be possible.

On my first visit to the Bethlem, I was introduced to all the members of staff. I was also invited to discuss any issues with and ask questions of and with the Staff Nurse and Primary Care Nurse, invited to ward rounds once a week at a time to suit me and asked to collaborate in my daughter’s care from day one. Her consultant questioned me, listened to me and expected me to be part of the team. The staff were endlessly supportive and kept me informed as to any changes in my daughter’s wellbeing, kept in touch with me and offered advice – and, above all, we all trusted each other. The consultant’s attitude was that if I was not strong, healthy, informed and trusted, how could I care for my daughter when she returned home? The entire turnaround of my former experiences enabled a leap in my recovery.

Recovery, if that’s the right word, is, for me, support with the role of caring. Knowing that someone is in the background relieves some of the fear and anxiety. Trust and willingness by the services not only to listen but to hear, exchange ideas, be ‘there’ for you and be willing to jump if the need arises are crucial. Unfortunately, with a diagnosis of schizophrenia, the journey of recovery is similar to that of a roller coaster ride. It is dependent on my daughter’s mental state. Currently she is stable but, if she missed her medication for more than 72 hours, we could be thrown back to around square one, which from my point of view means that recovery is relative. I was warned early on that this diagnosis could be likened to all the stages of bereavement but without the death; in other words, there is no closure. My ‘recovery’ is not complete, and of course it never will be, but with my care of my daughter and her subsequent blossoming, my ability to ‘read’ her mental state and the knowledge that I have back-up, I can remain in a state of what I would like to call ‘recovering’.