

A CARER'S EXPERIENCE OF THE MENTAL HEALTH SYSTEM

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My experience of the mental health system started in the mid 80s, when I was concerned that my son was dyslexic and I requested a consultation with a specialist. The specialist informed me that he wasn't dyslexic—despite my son receiving no tests—and I was told that I was worrying unnecessarily which did not help my son or alleviate my growing concerns about my son.

My son was highly intelligent and exceptionally gifted in chemistry. His peers repeatedly teased him by calling him a 'boffin' and his discomfort was heightened when a teacher jibed at his intelligence. He had few friends and my son began to struggle with getting up to go to school. When I was at my wit's end to know how to help him, I requested an appointment with a psychiatrist.

Both my son and I were seen separately. He was acutely distressed after each appointment and refused to see the psychiatrist again. The situation at school continued in the same vein yet despite his distress he obtained nine GCSEs at top grades. Two years later, however, on the first day of his A-level exams, he told me that he had absconded and spent the day cycling in the country.

That autumn found him at an Adolescent Unit, diagnosed with depression and anxiety. With the help of the unit psychologist, he became less withdrawn and more interactive—making friends with a fellow patient. Because of his age¹ he was discharged, and returned home without any psychological support in the community. On challenging the GP about the absence of support, I angrily demanded, 'So, what do I do now? Bring him back when he is thirty?' There was no reply.

My husband and I encouraged our son to go to college and he passed three A-levels with high grades and was accepted at university to read chemistry. However, his levels of anxiety were so high in the presence of other people, that within a few weeks he withdrew from the course. Two years later on a second attempt, he withdrew again.

Meanwhile he was prescribed various antidepressants and was referred to a psychiatrist in another health authority who arranged a place at an anxiety management group. My son was unable to tolerate the stress he experienced in this situation and after a few sessions stopped attending. The NHS responded by letter, stating that since my

Note: All names have been changed and details modified so that no person is identifiable.

1. He was too old for the unit, having turned eighteen.

son was not bothering to attend the group, his place would be given to another patient who would be more appreciative. The underlying message was clear—because my son failed to attend appointments, they were shelving all their responsibility towards him. It was almost as if they had come to the end of the line of their expertise of help and care. No member of the psychiatric team had contacted my son to find his reason for non-attendance or taken any interest in how he experienced the anxiety management group. Yet again, my son was left to cope with his difficulties without professional help. I felt that the system had deserted both of us. I realised that the task of helping my son with his difficulties in functioning adequately within the adult world was once more on my shoulders.

In 1994, through my encouragement, he began to work on a voluntary basis, acting as an escort, taking the elderly to local clubs. Initially he found the work difficult. However the elderly people had a high regard for his thoughtfulness and care, which he instinctively showed towards each individual. His confidence grew and he increased his involvement in this line of work.

In 1997 he was employed as a trainee butcher, with the full assurance of being trained as a butcher. He worked hard to learn the ropes. As the days went by, he became aware that his position would be terminated when the head butcher, following chemotherapy treatment, returned to work. My son was dismissed on Christmas Eve, six weeks after commencing. Feeling deceived, his depression returned. As his depression deepened he was prescribed Prozac. As the Prozac dose was increased, he began to experience vivid nightmares and acted on them as if they were reality-based—giving a large sum of money to charity. I later read that nightmares are amongst the adverse effects of Prozac.

Another unwanted effect of Prozac is psychotic experiencing, and in the year 2000, my son's acute psychotic crisis experience led us both into the next stage—the inner world of the mental health system.

My husband had lain awake all night listening to my son having verbal conversations about religion in his bedroom. Our offer of help was angrily refused and fearing that this situation had the potential of becoming violent, I sent my youngest son down the road to a friend. I waited for the surgery to open to contact the GP. The receptionist told me I would have to wait until surgery finished—another three hours. In the interim period my son tore out of his bedroom, hurtled down the stairs, shrieking and screaming in terror. I was terrified and hid behind the sitting room door, dialling 999. My husband led my son into the kitchen and managed to reassure him. On our drive stood three police cars and an ambulance. I just shook from head to toe with shock as I went out to speak with the police.

When the GP arrived, she seemed more concerned about our impingement on her off-duty time than with our situation. She gave a prescription for Diazepam 2mg tablets and called out the crisis team. We tiptoed round the house, speaking in whispers and wondering if my son would explode again.

After four hours, the crisis team arrived. They seemed efficient and escorted us to the acute ward. A nurse took charge of my son and he was led away from us with her

words ringing in my ears—‘You may see your son provided he gives permission.’ My heart sank. I had cared for my son for twenty-five years and here was this stranger who appeared to be severing my connection with my son. I thought she was callous and cold. I felt dismissed, bewildered and hurt. I asked for the ward phone number and we left.

That initial experience set the tone for me. I lay awake that night and resolved to be as fully involved as possible in the care of my vulnerable son. My son had entered this inner world of the mental health system. And so had I. My commitment to be alongside my son enabled me to learn and inwardly digest the intricate subtleties and nuances of the mental health system.

Whilst he was an in-patient I telephoned frequently to enquire how he was doing and visited him daily. We discovered that the psychiatrist made all the decisions at the ward round, which my husband and I thereafter attended even though it disrupted our working commitments. In these meetings, it was often the case that the nurse presenting my son’s psychiatric state had very little to do with my son and occasionally had not been in contact with him at all.

Within two weeks the Responsible Medical Officer (RMO) diagnosed schizophrenia. He discontinued Prozac abruptly and began treatment with an atypical neuroleptic. The pharmacologist stated that he would have to take medication for at least twelve months. We weren’t informed about adverse effects—we learnt about these as the neuroleptics took a hold over my son.

My son was discharged after three weeks. I was relieved. He seemed all right and was pleased to return home and be back in his familiar surroundings. My complacency was short-lived, for three weeks later he experienced his second crisis. On walking to the ward my son suddenly surfaced into our shared reality and asked whether he was schizophrenic. I was distraught and avoided answering his question.

Initially I had trusted the mental health professionals with their knowledge of schizophrenia together with their psychiatric treatment, but in the following months as my son launched from one crisis to another I began to feel insecure and uneasy about the treatment he was receiving. His quality of life was poor and so was mine. What I couldn’t understand was why on earth hadn’t the medication been effective for him.

I began my own research into schizophrenia and neuroleptic treatment. The research I discovered contained information which professionals had failed to disclose to either my son or myself. On reading how the neuroleptics were impacting on my son’s central nervous system, I felt a deep sense of revulsion. I could not believe what the treatment was doing to my son’s brain tissue and it took me many weeks before I could fully take in all of this information. My trust in the mental health system plummeted to rock bottom.

The many crises my son was experiencing appeared to fit in with the academic literature about Super Sensitivity Psychosis (SSP). I realised that my son’s extreme sensitivity to medication resulted in him being over-medicated and the neuroleptics were actually inducing and perpetuating his psychosis. The prevailing psychiatric belief that neuroleptics are *anti*-psychotics appeared not to be the case for my son.

When I took this factual research for my son's Multi Disciplinary Team (MDT) members to read, professional people would not give their opinion on it, despite it appearing extremely relevant to their neuroleptic treatment of my son. Invariably his SSP crisis resulted in the RMO attributing it to a 'relapse'—a worsening of his illness and further evidence of schizophrenia. His medication was either increased or changed to a different neuroleptic. It all seemed so random, rather like neuroleptic roulette.

When my son realised the neuroleptics were having a negative effect on his quality of life, he tried to withdraw from neuroleptics. My husband and I supported him. Due to our ignorance of neuroleptic withdrawal, he experienced a psychosis. The RMO regarded this psychosis as still further proof that my son needed to be medicated—giving the psychiatrist additional weight to his prescribing even more neuroleptic treatment. I perceived that this psychosis was connected with withdrawal and in line with my research into Tardive Psychosis. My son had basically gone 'cold turkey'.

On another occasion when the RMO withdrew my son's Lorazepam too abruptly, he began to experience psychotic symptoms within twelve hours. On a different occasion, six weeks after being admitted into a closed unit my son began to despair that he would ever see his home again. He became acutely distressed and experienced greater trauma through hallucinations. The MDT attributed my son's psychosis to his schizophrenic illness, to the exclusion of any other possible rationale.

In the same way that every psychotic episode was attributed to the presence of 'schizophrenic illness', the ward staff and professionals moulded my son's behaviour into the disease symptomatology. Negative symptoms² were also attributed to 'the disease'. For example, the RMO repeatedly stated that my son's deadpan expression was the negative mask of schizophrenia. Each time I would patiently point out that he had a facial paralysis resulting from an ear tumour. My son became overwhelmed during the ward rounds—his body shook violently and he became mute. The nurses believed that these were further negative symptoms of schizophrenia. I pointed out my son only shook in the presence of a group of people, because of his increased anxiety.

Another 'negative symptom' related to my son's lack of personal hygiene. I queried whether any MDT member had taken an interest in asking what difficulty my son was experiencing with his hygiene. On asking my son, I discovered he was reluctant to bath because the towels did not dry effectively and there was no change of clean clothing. These are all valid apsychoic reasons for not bathing and at that particular time had nothing at all to do with negative symptoms.

My son experiences difficulty in making 'small talk'. The MDT classified his withdrawn and antisocial behaviour as part of the negative symptomatology. I repeatedly emphasised that my son has Asperger Syndrome and his preference to avoid socialising is an Asperger trait. My son spoke fluently and intelligently about Formula-One racing, and stocks and shares, when interest was shown in engaging with him about these topics. The emphasis on symptomatology seemed to distract the professionals from

2. Negative symptoms include apathy, lack of motivation, emotional flattening, withdrawn behaviour, difficulty in concentration and cognitive functioning and reduced curiosity.

taking an interest and seeing my son as a whole person in his own right. It seemed as though they couldn't see beyond the disease.

He was quizzed about voices and odd thoughts on a daily basis. This has posed problems since, having Asperger Syndrome, my son interprets verbal communication literally and will respond concretely. He became increasingly confused with their questioning. For example, when another person speaks, he hears the voice of that person speaking and on subsequent questioning if he has heard voices, he would often reply affirmatively because he has just heard the voice of that person.

On most occasions when I spoke to the RMO and Care Trust Managers about schizophrenia and neuroleptic treatment, I was looked at with incredulity, as though I had no right to comment. This was confirmed when I was told by the Mental Health Commission psychiatrist in no uncertain terms to leave such matters to them, the professionals. I got the message loud and clear. As a carer, they regarded the treatment of my son as none of my business. I disagree—this *is* my business when I see what my son has been made to suffer.

Within a few days of starting medication with a neuroleptic, he began to suffer Parkinsonian-induced shaking and the standard anti-cholinergic drug only gave him minimal relief. Akathesia,³ yet another adverse effect, made my son pace up and down the corridor continuously. When he was at home he walked round and round the house and up and down the garden. Trying to settle down to watch television or read was an impossibility. His only relief was when he was asleep. This inner restlessness became so intolerable that my son said he would rather commit suicide than to suffer in this way for the rest of his life.

After one year my son began to develop involuntary facial movements. These included the blowing out of his cheeks, puffing though his lips and the protrusion of his tongue—his mouth looked full of tongue and eating became difficult. I recognised these as symptoms of Tardive Dyskinesia (TD). I had been dreading this, as I knew from my research that TD is potentially irreversible. Many older people develop these facial movements—it is a part of the aging process and results from the degeneration of the nerve endings in the brain. I was so concerned that I requested a referral to a neurologist for my son to be assessed. The RMO delayed this request indefinitely. A new RMO in the ward round placed emphasis on how 'the benefits outweigh the risks' regarding medication—as if acknowledging my son had TD but that this was acceptable because of the benefits of the drugs. We then received a letter from him which declared that in his opinion my son was not suffering from TD. This seemed to be an attempt to absolve himself from taking responsibility for the damage to my son's brain, brought about by his treatment.

Eventually two private neurologists diagnosed my son's TD and recommended that the neuroleptic drugs be discontinued, in accordance with pharmaceutical literature surrounding TD. Despite this, at a later date an NHS neurologist claimed that he did not know the reason for my son's facial movements. This NHS non-diagnosis was

3. Akathesia, an adverse effect of neuroleptic medication, is involuntary inner physical restlessness.

upheld for three years before one NHS psychiatrist finally acknowledged the diagnosis of TD.

I am aware that doctors in general medicine regard the deterioration of body organs as an important reason for discontinuing medication, in order to avoid further damage to the patient. I think this is caring practice. In psychiatry doctors seem to consider that physical signs of brain degeneration are trivial, irrelevant and unimportant. I do not consider this psychiatric practice to be caring—as far as I am concerned the 'risks *far* outweigh the benefits'. As the months and years have passed, my son has been admitted onto many different wards and units. He has experienced treatment from sixteen RMOs, every one of them being involved in sectioning situations in which the mental health professionals take absolute control over my son. The resulting professional relationship with my son is unbalanced and open to abuse.

I have found that coercive behaviour has been commonplace. A social worker, who I had entrusted to see my son alone in our home, told my son that he would extend his section for another year if he did not comply with attending group therapy. My son was left crying uncontrollably. One RMO stated that since my son had difficulty in expressing himself—she thought it appropriate that he should be sectioned and yet another RMO stated that he would extend the section until my son spoke about his problems. As a caring and responsible parent, I feel incensed when my vulnerable son is threatened and I am sure that threatening behaviour is not conducive to a trusting relationship.

In a closed unit, my son felt professionally badgered for six months, due to the pressure from the Multi Disciplinary Team (MDT) who wanted his agreement to increase medication. Browbeaten, he eventually succumbed in a Care Programme meeting. His statement was duly recorded and acted upon immediately by the RMO. In private my son told me his reason for finally agreeing—he just wanted to get them off his back. He also thought that if he was obedient and complied with their need to increase medication, he would be allowed to return home. This did not occur for many months since there were indications that the unit guidelines directed staff towards keeping my son locked up for a year, followed by another year locked up on a closed rehabilitation unit.

Not one MDT member showed any interest in why my son had suddenly succumbed to accepting an increase in medication, despite his repeated statements declaring his need to come off medication. I witnessed staff repeatedly ignore my son's plea to come off medication and to return home. When he stopped asking to return home, I asked him why. He replied, 'What is the point? They never listen to me.'

One RMO gave my son the option of not taking neuroleptic medication. On choosing not to take the medication, the psychiatrist then stated that if that were the case, she would have him sectioned so that he would have no alternative but to take medication. As my son and I left the ward round he said, 'She has trapped me.' I agreed with him. I thought her statement was manipulative and I felt intimidated by her threatening attitude.

As a routine, my son is *told* what neuroleptic to take and is *told* that if he stops taking the medication he will become ill. This emphasis on medication is further coercion intended to frighten him into submitting to treatment he does not want. Sometimes

though, staff bypass any discussions, coercive or otherwise about treatment and instead simply use their ability to section him. My son and I have experienced the full weight of the legal sectioning power, which on one occasion enabled the RMO to medicate my son with high disastrous consequences.

The RMO in question embarked into a Section 3⁴ without informing my husband, who is next of kin, in order to commence treatment with Acuphase. This treatment resulted in my son becoming so sedated that he was unable to stand or sit unsupported, he urinated on the floor and fell asleep with mouthfuls of food. As the medication wore off he became increasingly aggressive and psychotic. The psychiatrist, however, insisted that the course of treatment was completed and due to my son's uncontrollable physical aggression he was transferred to the Intensive Treatment Services (ITS).

I went to the Unit. The nurses had resorted to basic nursing care as my son had become as a little child. He showered with a teddy bear under his arm and took teddy to bed. My psychotic son refused an ECG when the staff were concerned about his fast heart rate. Despite their concern about his heart, this was a significant adverse effect they did not address. He looked terrible. Saliva dribbled constantly from his mouth, making his T-shirt sodden. He lost his hand-to-mouth coordination and lost a stone in weight over a period of one month as he was unable to feed himself. His speech was so slurred that even I wasn't able to understand him. My pleas to the nurses went in one ear and straight out through the other. When the RMO returned from holiday, he increased the routine neuroleptic. My son's reddened eyes began to protrude from his eye sockets. I thought he was going to die. I went to a friend and sobbed in despair with all this unwanted and needless suffering that both my son and I were being legally forced to endure. That afternoon a nurse from the previous ward made a routine visit to the unit. On seeing my son's physical deterioration she recommended that the neuroleptic be reduced.

Many of the signs and symptoms that my son experienced in that terrible time are described by Neuroleptic Malignant Syndrome, a potential life-threatening situation. It transpired that before the Acuphase treatment was started, half of the MDT had wanted this Section applied because it provided legal protection in the case of my son's death. Another RMO in a sectioning situation did declare that he was endangering my son's physical life but he would take full clinical responsibility.

I am absolutely appalled by these situations in which it is clear that psychiatrists can do anything they want to do with my son regardless of the consequences. I want my son alive not dead. I want a doctor who truly cares about my son.

Because of the medication, my son is more prone to having cardiovascular disease and I am aware that he could suffer from a neuroleptic induced heart attack or stroke, or die from a seizure or respiratory arrest. He will become sterile as well as impotent. As the medication continues I know my son's life span is being shortened as the medication accelerates his aging process and I know one day he will look more aged than his father, and TD is associated with dementia.

4. Section 3 is part of the Mental Health Act which enables a person to be detained in hospital for a six-month minimum period for treatment.

My son was getting worse, not better. He was receiving all sorts of different medication treatments, but only medication. He had not received any psychological help at all. I was told that psychological treatment was not included as part of treatment on the acute ward. My husband and I worked hard to persuade one RMO along these lines by influencing the Trust managers to allowing a special provision for 'talking treatment' for my son. Part of this 'talking treatment' necessitated my son writing down his hallucinations and delusions, together with the potential triggering factor with the date and time. Although he attempted to write a few of his experiences, this exercise posed him some difficulties. His concentration was impeded due to the sedation effect of medication at that point in time. Another side effect impaired his cognitive functioning making it harder for him to work things out. It transpired that the psychologist's input was primarily designed to correct my son's behaviour in order to ease the nurses' management of my son. When he was acutely psychotic on a closed unit, a PSI (Psychosocial Intervention) psychologist stated he was too psychotic for therapy. Neither psychologist made progress and both gave up, my son being classified as unsuitable for therapy.

My distress at seeing my son constantly psychotic propelled me to pluck up courage to try to link with him by trying Garry Prouty's Pre-Therapy contact method. I felt greatly encouraged when I found that I was able to decrease his distress by grounding him back into our shared reality. As I developed an interest in this approach, I also became more aware that some of his body language and fragmented words were connected with situations from his past. I realised that his hallucinations had some meaning for him. This seemed to be an alien concept to professionals who saw his psychotic expressions as unimportant and needing to be stamped out at all costs; no one considered his psychotic experiencing to have any potential value in helping my son in the long term.

My son eventually realised I was able to help him in this way and would frequently ring me at home pleading with me to come and ground him saying that the nurses did not know what to do.

On discovering I was able to help my son, I made contact with Professor Prouty, who invited me to a Pre-Therapy International Network meeting and I eventually attended workshops by Professor Prouty and Dion Van Werde, the Lead Psychologist at the St-Camillus Hospital, in Ghent, Belgium. I realised Pre-Therapy provides the vital link which is essential for all professionals to be able connect with people experiencing psychosis—enabling them to have meaningful conversations. I began to share this knowledge with various Care Trust personnel. CBT (Cognitive Behavioural Therapy) and Psychosocial Intervention (PSI) psychologists were uninterested, preferring to focus on their particular approach. One nurse seemed to find my knowledge threatening and became defensive, claiming she had nursed and managed patients for over twenty years. Only one nurse who was present when I was working with my son realised that I was able to link in with him.

Because of the minimal interest shown, I decided to search further afield and made contact with universities and Care Trusts. A Reader in Mental Health at the University of Central England recognised the importance of Prouty's work and supported me in several Pre-Therapy taster workshops. Many people showed interest

and I received positive feedback on several occasions although following one presentation, the presiding nursing tutor told her students that if they used this skill they would be struck off from the course. During a telephone conversation, a psychiatrist from a high-secure hospital said, 'You might as well teach your grandmother to suck eggs.' I felt insulted.

Some of my lowest ebbs occurred when my son was detained on the ITS and the low-secure unit. Both of these situations are closed wards, where access to see my son was through three sets of locked doors and I had to make arrangements with staff prior to visiting. On many occasions I was not able to visit my son because of 'clinical activity' in these units. On one unit I was not allowed into his room—visiting took place in a tiny open communal area or in the dining room. There was always a nurse within earshot and despite reassurances that we were not being overheard, a nurse would frequently interrupt our conversation. This was a gross and completely unwarranted invasion of our privacy.

On one occasion when my son began to get annoyed with the staff, the nurse in charge suddenly grabbed hold of my son and physically forced him into the isolation room. When the nurse finally came out I asked to speak with him in private. My husband joined me as I confronted this nurse's 'manhandling' of my son in a situation where my son's annoyance could have been resolved less aggressively. After half an hour of tussling with this nurse's denial of his aggressive physical behaviour towards my son, he apologised, realising that he had been heavy-handed. I respected him for his apology and my son was treated with more respect in my presence. In my experience, apologies for inappropriate behaviour have been exceedingly rare.

During my son's Tardive Psychosis resulting from Lorazepam withdrawal, he became increasingly delusional eventually refusing our requests for visits. He told the MDT members that he did not want either my husband or myself to know anything about his treatment or progress. Each time I rang I got the same answer from every nurse. They told me they had to respect my son's wishes and confidentiality and refused to tell me anything. This went on every day for two weeks. I had no idea how my son was faring and we were not able to give him support at the ward rounds. I began to despair as my connection with him appeared to be severed and feared that this was the final cutting-off point in the care of my son. I was worried that this would be only a small step away from him disappearing forever into a succession of medium- and high-secure units without me having any knowledge whatsoever regarding his whereabouts.

I knew I had to do something. The one connection I still had was with the nurses. I rang the ward once again to see how he was, saying I felt totally cut off from my son—I was his Mum after all and I needed to know how he was doing. The ward manager gave me the same response about respecting my son's confidentiality. I told her that my son was delusional and did not have an informed choice about our support and involvement in his care. She continued to listen. I went on to say that if, in my son's delusional state he wanted to have oral sex with the male staff nurse, would all the MDT members respect his delusion? To my enormous relief, she then proceeded to tell me

how he was. My challenge to the nurse regarding his delusional state slowly filtered through to the staff, who eventually encouraged my son to see us both again.

In this inner world of the mental health system, I experienced professionals acting like gods, who reign supreme within their 'received medical wisdom'. I experienced professionals' rigid compliance with treatment in relation to national and local policies. When I introduced them to published research, I met their resistance, arrogance and superiority. I have felt powerless to help my son in sectioning situations and vulnerable in the face of their power and control of my son. I am affected considerably by these 'professional attitudes' and how their behaviour impacts upon their relationship with my son. Needless to say my son is also affected.

On one closed unit I realised how scared he was of interacting with MDT members. When he was apsychoic I used to encourage him to stand his own ground in relation to the nurses. He would reply, 'I must never upset the nurses'. This situation, where my son had to spend twenty-four-hours-a-day minding his Ps and Qs, is asking something practically impossible of *any* person. It is as though in being careful to stay on the 'right side' of the MDT members, he was actually protecting the staff from their own difficulties in their relationship with him. Furthermore, whenever my son was given extra medication, it always seemed to be the same nurses on duty. It was as though my son appeared to be more distressed in the presence of some nurses rather than others.

My ultimate frustration and exasperation was when on a closed unit, the MDT members made a united stance in refusing to help my son with Prouty's contact work. Seeing my son being needlessly distressed at the expense of this collective decision, I began to confront their psychiatric practice together with professional attitudes and behaviour. The MDT reacted defensively by involving the Trust managers, who summoned myself and my husband to a meeting. Their issues included, disproportionate amount of time spent dealing with us as relatives; attitudes, behaviour and manner directed at staff; and difficulties arising from differences of opinion regarding treatment and its consequences. Initially I felt threatened. Then I realised that I was receiving all the blame for these issues. There was no indication of professionals' accountability for their behaviour in our relationship. It was as though all their behaviour was impeccable and unquestionable. I certainly didn't feel understood in my distress.

Similarly there were many occasions when no attempt was made to understand my son when he was distressed. For example the nurses used CBT reasoning techniques to modify my son's physical aggressive behaviour, such as 'When you stop hitting out I will let go of your arm'. When the nurse let go of his arm, my son lashed out again. In these times of emotional distress, *he* always had to understand what the nurses wanted from him. For their part, the nurses made little or no attempt to understand the reason for his anger or what it was like to be in his shoes. Not being understood only served to heighten his distress.

On another similar occasion he was refused home leave. The nurse abruptly left him without seeing what effect this damning news would have on him. My son reacted once more by lashing out. He was pounced upon, manhandled and frogmarched down to the isolation room. When the door opened for him to be given extra sedation I could

hear him shrieking in anger and indignation. I offered to sit with him. Sitting beside him, he began to sob profusely. We returned to his room, where he verbally let out his vengeance towards the nurses. I reflected what I thought was going on for him. 'You're angry and all you want to do is to hurt the nurses.' He nodded. 'You want to come home. I want you to come home. I am not sure how we are going to manage this, but we will work on this together.' I watched my son's face as my understanding of his dilemma began to seep into the core of his being. He felt understood and became calmer.

Many times during my interactions with professional staff, I experienced their cool, polite indifference and silence. Sometimes I had difficulty knowing whether they had understood the gist of my communication. I felt I was trying in vain to relate with people who had turned into stone, and yet when I heard laughter and lively conversations with drug representatives, I knew they had a warmer quality, with more openness in their relationships with other people. It seemed to me that in their professional relationships, their ability to be more human was stifled. I decided that there must be a way of reaching through to this important part of them, so I began to search for some of their humanity. The following are examples of what happened when I tried to relate to the staff as *people*.

When one nurse informed me that medication had not been discussed at the ward round because my son had failed to attend (stressing it was my son's responsibility to attend at the ward round) I explained that my son experienced high levels of anxiety in group situations and found the ward round difficult. I asked the nurse whether he had been in a similar position of being the subject of discussion surrounded by a group of people. He said that this was personal and it was his prerogative not to answer. His refusal or inability to be upfront with me ended our interaction.

Because of my dissatisfaction, I approached the staff nurse and asked him the same question. Slightly hesitantly he answered that he had been involved in similar situations and had felt most uncomfortable. He said he was able to understand how my son felt. Although he was probably taking a risk with his response, he was open and authentic. He did not hide behind his professional façade—we were able to talk on the same level as equals, and were able to continue our conversation.

On another occasion I told a nurse how upset I felt at seeing my son suffer with TD and EPS. I asked her opinion about the drugs. Her response was automatic, telling me that her role as the nurse was to dispense the medication. Recognising her aloofness, I gently pointed out that she was talking from behind her professional position. 'I want to know from you, Agitha, what you think.' Eventually her face and her tone of voice changed, becoming softer as she slowly said that she would not like to be in my position, as a mother seeing her son suffering with the results of medication. My heart warmed to her. I had reached through to her as another member of humanity.

In these latter interactions, when I have managed to find others' humanity, I have felt deeply respected and validated as a person of worth and value.

On all of the occasions when the RMOs have denigrated my son by saying he will need care for all his life because he is schizophrenic, I doubt they were aware of the

negative impact their words have had on him. The result was that my son basically gave up striving to make a living—he could survive on handouts from the Department of Health and Social Security for the rest of his life. The diagnosis compounded his belief that he would never, ever, achieve anything in life. It was terrible to see my son hammered into the ground in this way. I need professionals to validate my son's intrinsic worth and value, so that he will gain confidence and move forward in life and achieve his full potential. However, overall he has experienced relationships where support is virtually non-existent. It has only been on rare occasions that he has felt respected and supported.

One staff nurse told me that my son appeared to respect her more than the other nurses. It transpired that this nurse set boundaries, gave clear communication and was genuine when interacting with my son. In a nutshell, by having a strong personal boundary, this nurse respected his own person and therefore was able to respect and support my son. My son, in his sensitiveness, perceived the nurse's genuineness, returning the respect in kind.

One support worker inadvertently referred to her strong personal boundary as she accompanied my husband and myself through locked doors—she suddenly turned around and told us how she could understand our concerns over the treatment of our son. Sensing her genuineness, I asked her why she, as a support worker, was able to understand when the professionals weren't. She replied that she had 'broad shoulders'. She gave me a hug and my whole being filled with her warmth. For once, my faith in humanity returned.

Before my son entered the inner world of the mental health system he had difficulties. Five years later those original difficulties are still there and are now compounded with problems arising from by NHS treatment and the professionals' ways of relating, which I think are tantamount to physical and emotional abuse.

My son did not ask for this; he does not need this. And I feel betrayed.

By hanging on to my son by the merest thread, he is now back home. Over the months within our supportive and caring environment, he is becoming more secure.

In public he is still incredibly vulnerable. His facial and body movements make him look odd, so losing credibility in society. His life has been directed, controlled and dominated to such an extent that any vestige of self-empowerment has been scuppered. It is as though his very being does not belong to himself any more. Any feelings of trust have long since disappeared. He is like an empty shell. I wish with all my heart that this was not so. Beneath my anger is my ocean of sadness. When my sadness washes over me, it is replaced by my love for my son, which provides me with an inner strength to carry on.

If I can hang on to my deep-seated belief that in every person there is the potential for a change of heart, then I do have a glimmer of hope. I believe that the key lies with those professionals who are committed to their own personal development towards strong personal boundaries. Only in an environment where professionals embrace others by being open, upfront and genuine in caring for others as members of humanity, do I believe my son would be in receipt of a healing relationship. Within his shell there remains a hidden pearl, which can be reached, touched and revealed as the person he truly is.