

“Between a Rock and a Hard Place”

How Orthodox Psychiatry transforms a Crisis into a Way of Life

My world turned upside down in 2005 when my daughter, Alice, attempted a very serious suicide and almost died. “A very close shave” was what the hospital consultant told us in the Intensive Care Unit a couple of days later. Less than four weeks earlier, Alice had been prescribed anti-depressants and sedatives by the local Crisis Resolution Home Treatment Team, following a long period of depression and suicidal thoughts. Leaving her at home with me rather than opting for hospital admission, the team visited us almost every day to assess progress. After two weeks, a member of the team decided that Alice was showing signs of psychosis and gave her anti-psychotic medication. We were given no explanation or choice about this – just a statement that she would improve once the tablets “kicked in”. Although worried about extra medication, we trusted them because we considered them to be the experts on mental health. How wrong we were ! The anti-psychotic had a devastating effect on Alice. She became extremely distressed within half an hour of taking this medication. She seemed even more confused, whilst becoming very quiet and withdrawn. Much later, she described the experience of taking the anti-psychotic as being like “a shot in the back of the head” – much more confusion arose. Over the next few days Alice became visibly more sedated and stupefied, whilst I became much more anxious and worried. One morning she left the house at 8 am and, fortunately, I managed to persuade her to come back in. She told me much later that she had left in order to find a high building or bridge from which to jump because she felt so unwell. At that point, I had to lock the door and was advised by one of the team psychiatrists not to let her out on her own. So

now, Alice was virtually my prisoner ! She was almost 24 years old at the time, but I didn't think about the legal ramifications of doing this as I was more concerned that she was safe.

Throughout these very difficult weeks at home, Alice was asking to come off the medications which she felt were not helping her at all. The team were reluctant to do this at first but agreed to do so eventually as she was clearly not responding well. However, they told us they were unable to do it immediately as there was no psychiatrist available to supervise the withdrawal over the next few days. I think this was when Alice and I were both at our lowest point, somehow realising that these medications were not going to help her, but that she had to stay on it even longer than necessary – with no definite plan about when she could stop taking it. It felt like a punishment. We were both exhausted and confused but I sensed that Alice was really feeling she had had enough. A couple of days later, following a visit from the team when she even told them she still felt suicidal, Alice attempted to take her own life. Being on 'high alert' myself and sensing that something was wrong, I managed to find her just in time to prevent her death. The shocking, horrific experience which happened on that day is forever etched in my memory and it is one that Alice would rather I did not have – the day when my daughter may have died and become just another mental health suicide statistic.

I believe that this horrific and traumatic initial experience led to my growing distrust in the mental health system. I was deeply traumatised and needing support myself. My feelings were complex, my thoughts confused and my passion for justice was aroused. A few months later I lodged a complaint about this home treatment service because I wanted an explanation for myself and especially for Alice. I wanted to know why my daughter had nearly died under their so-called treatment plan. After following through on my complaint ,

I took legal advice and established that the Home Treatment team were guilty on several counts. In particular, they had given Alice two medications that were likely to enhance her suicidal ideation and, therefore, she should have been closely supervised in hospital. The Trust settled out of Court with a relatively small sum of money, but I at least felt satisfied that we had discovered the truth. Alice explained much later that the medications were making her feel worse, confused, anxious and more suicidal. She had thought of different ways to end her life and felt compelled to do something to stop the unbearable bodily sensations she was experiencing. She thought nobody knew what to do and believed her death was the only way out – to resolve the issue.

Even after her attempted suicide, further psychiatric medications were given to Alice in hospital, with no other treatment offered. One anti-psychotic began to affect her appetite immediately, increasing her usual weight from 140lbs to over 200 lbs within 6 months. The fact that the drug had a major sedative component did not help either. Alice has gained even more weight since then, leading to worries about possible diabetes, heart problems and metabolic syndrome. It is a well-known and documented side effect of these medications, but nobody in the mental health services seemed to think it was a problem !

Following the completion of her degree in textiles and prior to her crisis in 2005, Alice had been actively seeking work. After such traumatic events, hospital admissions, and the adverse effects of the medications, she found life much more difficult. Her life seemed shattered and it took time and effort to pick up the pieces and find some sort of order again. Alice was given a diagnosis of depression with psychotic features at first. This was later altered to schizo-affective disorder and sometimes she was labelled with other diagnoses such as bi-polar. Being assigned a diagnosis is a double edged sword. Without it, a patient

may not be able to claim benefits, yet the diagnosis itself can affect a person's self-esteem as it carries an incredible amount of stigma with it, both external and internal. The stigma of mental illness is very pervasive, both in society and within the mental health services themselves. Some professionals emphasised the "illness" as being a long-term disability which was not helpful. Psychiatrists were mostly interested in symptoms which might indicate a relapse and advocated long-term medication adherence. So where is the hope and how is one to live a life with some quality and meaning. Alice made valiant efforts in voluntary work and attendance at various courses, keeping in touch with friends and relatives. However, she found her moods continued to fluctuate and sometimes she would experience a manic phase which led her into risky behaviour which she now regrets. The fact she hasn't achieved what she had hoped for when younger leads to depressive and sometimes suicidal thoughts. Her lack of self-worth and confidence cause her to become depressed very easily and she often feels life is not worth living and is easily triggered into panic attacks. Her energy levels fluctuate due to her continual problems with weight gain, tiredness and exhaustion. The lack of good social engagement and a meaningful work life leaves Alice feeling very lonely most of the time. She sees her future as bleak and self-stigmatises, tending to see her past as problematic and full of mistakes made by herself and others.

So what about me – a single working parent, suddenly transformed into the role of Carer ?

Although I was in a very distraught state of mind and was on long-term sick leave, I was providing much needed daily support for Alice, both in hospital and at home. I managed to access therapy which continued for eighteen months whilst my GP prescribed me sleeping pills to help block out the continuous flashbacks. The mental health services offered me

nothing until I filed my complaint against them three months after the crisis. Two very good friends stayed with me overnight on a rota basis, helping me through those first few months. In all, I took a year off work, returning part-time until I retired six months later.

I spent much of my time with Alice, helping her to adjust to life as a patient. After several months, she began to make some progress and felt able to reduce and discontinue her anti-psychotic medication. Unfortunately, some of the symptoms of paranoia began to re-appear and she was admitted into hospital for a couple of weeks whilst a new anti-psychotic drug was introduced. Looking back, I now think this was a mistake and the situation could have been overcome without the reintroduction of more medication. I have learned much more about how a recurrence of symptoms can appear when withdrawing from these drugs. I was shocked to learn that there are no official guidelines for practitioners to use to help people withdraw from anti-psychotic medications. Consequently, people often stop taking them abruptly and experience extreme withdrawal symptoms and frequently a relapse, leading to further hospitalisations and even more medications. This does lead to many patients being told by doctors and psychiatrists that they need to remain on medications for life. This was certainly what my daughter was told when she asked to have her medication reduced and possibly withdrawn. Fortunately there are now websites on the internet explaining how it is possible to withdraw safely and slowly without medical supervision, but obviously that is not ideal as a solution.

Above all, admission into a mental health ward is not always helpful as other patients who use illegal drugs can easily influence vulnerable people. In fact, anti-psychotic medication can increase the vulnerability of a person and lead them into more risk-taking behaviour. This happened to my daughter and I felt at a loss to know what to do. She was supposed to

be in a safe environment, a hospital, but this was not the case. By this time, my nerves were shredded and I began to think that all was lost. A further 6 months after hospital discharge were spent helping Alice get over her psychological addiction to a dangerous illegal drug she had been persuaded to take by another patient. It took a lot of hard work on both our parts to get over this extra dilemma.

I began to realise my need to survive if I was to remain a Carer for Alice. I had not realised how much the mental health services would rely on me in the role of Carer and yet not support me. I was frequently not included in any treatment plans nor consulted over my daughter's care. One helpful intervention which I had to ask for repeatedly was eventually given by a psychologist who worked with us both together and separately. He was the only person who validated my role as a Carer being a very difficult one. He was also able to give me advice about how to manage the task of being both a mother and a Carer which helped me on a practical level and allowed me to consider my own needs as a priority. In fact, this advice eventually led to my decision to move out of London to a healthier environment and we moved to a smaller city in 2008. I did wonder whether the mental health services would be better in a new area of the UK as well, but was sadly mistaken. I continued to feel excluded from the mental health services in my role as Carer. I began to realise that I was a necessary economic asset to them, but was not regarded seriously as someone with a valid contribution to make regarding my daughter's mental health. The fact I was questioning aspects of the service probably did not place me in their favour. The issue of confidentiality raises many problems for professionals and makes it difficult for carers/family members to work in partnership. Although necessary in some cases, I now believe that "confidentiality"

is sometimes used as a smokescreen which allows the mental health services to exert exclusivity and power over patients/service users.

By this time, I had begun to wonder whether the treatment provided by mental health services could turn vulnerable and distressed people into long-term patients by introducing them to a way of life dominated by the bio-medical model. I was keen to find alternatives to that model and I joined a group of people looking to set up a Soteria House. I also began to attend conferences and read books about the anti-psychiatry movement. In this way, I gained knowledge and confidence over the next few years and became even more critical of mental health services. Meanwhile my daughter was experiencing more psychotic episodes and I was becoming increasingly concerned about the adverse effects of the medication on her, both mentally and physically. I was learning much more about the dangers of long-term dependency on these drugs. I couldn't understand why psychiatry continued to prescribe them whilst more research was showing how harmful the drugs can be, especially when used long-term. I began to realise that the majority of psychiatrists whom I encountered did not seem interested in anything except the dominant medical model. Fortunately, I have now discovered some psychiatrists who are critical of the model and do wish to see changes.

About five years ago, I heard about the Open Dialogue treatment for psychosis – a very successful system used in Finland over the past 25 years with very little reliance on anti-psychotic medication. Substantial interest in this way of working began to grow over time and now training in Open Dialogue is taking place within a few NHS Trusts in the UK. A large research study of the treatment is also taking place in the UK. One of these NHS Trusts in London is providing a service for people who are not in crisis, but wish to receive a different

approach from the usual treatment. The Service is called Dialogue First and my daughter and I are currently receiving a service from them. In contrast to the usual mental health services, I do feel included with Dialogue First as it embraces family members, friends and people in their network. The approach is so different, humane and inclusive. Everyone is able to contribute and the emphasis is on “being heard” and finding meaning rather than “treatment”. I feel it would have been so much more constructive to have had this kind of help 14 years ago during the first crisis. It has become clearer during our sessions with Dialogue First that much of Alice’s mental and emotional distress has been caused by several life issues – social, psychological, environmental, cultural, identity, etc. I do not believe that it is a disease or simply a chemical imbalance which medication can cure. Life is much more complex than that. However, it is a very long process to overcome 14 years of toxic medications, several hospital admissions, and the extremely traumatic experiences we have both suffered due to the lack of good mental health provision. Personally, I find it absolutely appalling that the mental health services continue to treat people with medication as a first line of treatment when there is substantial evidence regarding the many adverse effects when taken long-term, including diabetes, severe heart conditions, cognitive impairment, tardive dyskinesia, possible brain shrinkage and a much earlier death than normal lifespan. Who would want to receive such “treatment” which appears to be doing so much more harm than good? But what other choice do we have? What do we do when we are on the threshold of a crisis – when help is needed for people experiencing extreme emotional distress and they are at risk of possible harm? When the situation has gone far beyond what I can do on my own and I am exhausted through lack of support. I do not want to traumatise my daughter further by a possible mental health “Section” and hospitalisation plus more medications, but I cannot leave her to find her own way through it

without any help whatsoever. Living with this situation is terrifying, both for the patient/service user and for the Carer/family/friend. The crisis begins to escalate dramatically, no constructive help is available and the situation gets increasingly beyond our control – this is when I am “between a rock and a hard place”. This is when I would like to call on a service such as Open Dialogue – who I know would respond very quickly and provide a team who would help/support my daughter and myself through the crisis.

What can we do to bring about a change in the way our mental health services are organised, so that we can reduce our own anxiety and fear, and feel secure that when we ask for help, a service will be provided which does not turn a Crisis into a way of life for so many distressed and vulnerable people ?

I am now a member of the Open Dialogue Champions – a small group of family members/carers who have experienced the benefit of working in this alternative way. Our mission is to promote Open Dialogue throughout the NHS in any way we can, thus bringing about a transformation which will stop the overuse of psychiatric medications and the enduring damage this form of treatment is currently doing to our family members, friends and the wider society.

Ruth Smith

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