

## *Short Paper*

# Life with Schizophrenia and the Mental Health System

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doi:10.22158/sshshr.v3n2p49

URL: <http://dx.doi.org/10.22158/sshshr.v3n2p49>

This article recounts the symptoms of schizophrenia and the help I have had from the mental health system. After getting the first symptoms my social worker introduced the mental health system and the different stages you go through in the treatment of the illness, including hospitalisation and support from daycentres and sheltered housing once discharged. My social worker had a key role in delivering this help through monitoring the condition and providing care and support. Eventually I was able to live independently out in the community with the help provided.

### **My Life with Schizophrenia**

When I was young before the illness, I had heard of schizophrenia, but I thought it was something that affected other people and assumed it would not happen to me. Now looking back on this it seemed complacent and foolish to ignore such a possibility.

The onset of the illness was very gradual and started with a thought at the back of my mind I had done something wrong. It began to prey on my mind until eventually I ended up with the prospect of some terrible punishment and at this point the schizophrenia began to take over my whole life. The result was I was gradually losing touch.

I tried to hide from the neighbours, but they kept banging on the walls to force me out of the house. I had to escape them and that meant wandering the roads. I thought if I tried to explain this to anybody, they would think I am mad and I would be consigned to the loony bin as punishment, where there were dangerous lunatics.

Outside if the world thought I was mad it would be dangerous for me, though being in hospital seemed also to be dangerous so it was six and two three about being admitted or not. Eventually the distressed physically emaciated state became visible to friends and family, and I was forced under section into a mental asylum.

I felt the place I was living in was associating me with the terror that was going on, but the hospital stopped this reminding me of 9/11. My new surroundings began to be my safe place as therapists would tell you. I was living in mine. I felt like a social outcast for 9/11 but in hospital my needs were being cared for so this feeling stopped.

Once in there the banging noise stopped and the place made me feel safe. No one on the outside would come into the place because they thought it was dangerous so I could hide in there and be out of the way of everybody.

I was put on sedatives to sleep and was being warmed, fed and sheltered. My level one needs were being catered for. That opened up the safety level and I felt safe in there. After that I could engage emotionally with the staff and other patients which was a god send compared to being a social outcast and feeling terrified all the time.

I began to understand the hospital as a medical place since I was hearing voices about 9/11 and this required taking medication. There were some grounds for being there instead of being locked up for 9/11. So, if the outside world thought I was mad they would stop persecuting me.

Eventually there was some insight as the CIA never found me despite being under surveillance outside, but I felt if I left it to return to the community care I might be identified. Still, I didn't dare leave the hospital grounds in case the banging noise started again.

Living on my own would isolate me and the fear would shut down my emotions again, so this had to be handled gradually starting with supported living out back into the world.

It was decided that I should try living in a mental health project as given my delusional content I only felt safe within the mental health system where people around the place would see my thoughts as mad and not real.

This improved my mental health as I felt less confined than being in the bin and so I wasn't being punished for 9/11 in this way. It also helped with mood as this time I wasn't isolated by the paranoia.

I spent ten years locked in a room with this, so the feeling of confinement did not go but with proper finances and caring people around me I got through it.

Eventually I began to realise if I could control my thinking when out people would be none the wiser and I began to test this out with some mental health support which again just made me look mad to the other people.

I started by watching out of the window and found people were going passed without looking but I put this down to watching them in seclusion. It was necessary to do this when I was more visible to them.

So, I followed this up by driving passed people in a car. I had to practice looking at people without staring at then followed by making eye contact when out as in a shop or restaurants. Giving people guilty looks would give the game away it seemed.

I tried to take a Walkman to distract my attention from the people who might be watching me and that kept me thinking about something else other than 9/11. I wasn't concentrating on the paranoia.

Under these conditions the banging noise stopped but the thoughts about being under surveillance never went. I began to think they could not see my thinking if I kept away from them indoors.

This allowed me to get to a mental health day centre. There I found there were educational courses and activities which had never been provided in the old asylum and I began to take an interest in things again.

The problem was the thoughts about 9/11 never completely went and were often at the back of my mind so they were less noticeable. But often the delusions would be much more present to me, and this made them harder to disguise. I started to think about them more and more and if anyone saw me the consequences were terrifying.

Eventually I started to have some insight. I couldn't always hide my thinking about 9/11 but if people were seeing I was responsible how was it I had never been caught? Being thrown into the loony bin didn't turn out to be a punishment and was more of a sanctuary instead.

That realisation made it possible to have these delusional thoughts when around the other people without having to panic about the consequences. I began to calm down when out and could just let the paranoid thoughts in my mind to come and go of their own accord.

The happy ending is that with proper support I got to the point of living independently and outside the system despite the feelings of spied on. I began to calm down and enjoy life again.

### **Being Sectioned**

Social workers are very un-easy about forcing people into hospital under the mental health act and as this article recounts there are good reasons for this. It suggests solutions that could make being sectioned less traumatic for the service

During first contact with a social worker, you are being labelled mad or insane. They can make you feel a social outcast and cause much emotional pain. It feels like society is going to throw you into the loony bin.

It also immediately puts the stigma connected to schizophrenia on you and suddenly the world appears to be hostile. Again, this is very dangerous, and I was wary of the famous quote "opinion based on prejudice are always sustained with the greatest violence."

Being taken to the 'asylum' did not seem to be going to a place which was not a refuge from the outside world. I was expecting padded cells and straitjackets not a refuge from climate of prejudice, ignorance and fear that surrounds the world of mental health.

It had to be got across that they were trying to help with what I was going through and by calling it an illness they could treat it medically. I wasn't going to the asylum but to a mental hospital to provide care and support. The problem was that calling yourself mental sounded quite dangerous, so this explanation didn't remove the fear.

My family understood that schizophrenia was just a chemical imbalance and tried to reassure me that the hospital could correct this and look after me. The problem that the stigma was so powerful in shaping my perceptions I didn't believe them and felt betrayed. This was particularly painful and stressful.

The prospect of getting to the hospital seemed very dangerous as I imagined it to be full lunatics who were unstable and disturbed. I seemed very much at risks of being attacked most of the time and this would mean living in terror. It might have caused a nervous breakdown which would drive me mad.

Something that stood out in my perceptions was the language used by my social worker which reinforced all these perceptions. I was to be sectioned and this sounded too much like committed. I thought I was being certified insane rather than being diagnosed and this should have been explained.

I tried to resist being 'taken away' and the police were called and again this reinforced the impression I was going to be locked up. They again tried to convince me to go peacefully but I wasn't persuaded, and they handcuffed me and bundled me away in a police car. I wondered where they were taking me.

I had visions of never getting out and was remembering a song by METTALICA which frightened me. The lyrics were "welcome to where time stands still no one leaves and no one will." The place I thought was going to seem like a prison and I would have to fight to prove my sanity to get out. I had heard of care in the community but that again didn't make any difference.

At one point I began to have some cognition about the concept of being mental ill but because I thought of being responsible for 9/11 was real, I said I wasn't mad. Social workers didn't see it that way they thought I was ill and said they disagreed with me. I understood the medical side so far as it appears to doctors but didn't dispel my thoughts on where they were taking me so I continued to resist.

There is a possibility here that needs to be explored. The social worker can check for insight to make it less traumatic. If you understand that you are ill you could avoid the trauma of being coerced against your will. If you trust in your family, they wouldn't let any harm come to you the insight could be built upon.

The problem is that there is only so much insight you can have and there isn't time to go through weeks and weeks of cognitive behavioural therapy. Social workers will think there isn't time to explain everything, and it is better to get to hospital as quickly as possible to enlighten about all this.

The problem is that you will experience the fear and pain of being locked up on top of the schizophrenia which makes the whole thing particularly difficult. Being tortured for being responsible for 9/11 was absolutely terrifying but being locked up for it in with disturbed lunatics brought the fear to new levels.

In the end I was too weak to resist and gave into the pressure I was put under by the social workers, family and police. I was too weak at this point so I couldn't cope with that anymore. I had less strength to resist the symptoms now and the stress of all this produced a serious relapse. Once getting symptoms the stress of the illness perpetuated these and I became seriously unwell.

What it required was an explanation of the dreaded word schizophrenia not as psychopathic as this is the source of the worry the whole thing is causing when sectioned. It is not a dangerous split personality one half of which is dangerous, despite the story of Jekyll and Hyde.

What gets in the way here are all the different labels but these it should be explained are just slang and have been coined out of ignorance. Yet because they are in common usage, they seem to be what everyone thinks and that makes them seem meaningful.

What is needed at this point are positive media images that really explain mental illness but because their negative depictions it is going to require the professional image of the social worker, medical image of the doctor and the existence of charities like MIND and RETHINK.

Again, there is time to go deep into the nature of stigma but the general misperceptions underlying the labelling we are experiencing can be got across as it involves comedy, ridicule, fear, fascination and hostility. We can reclaim the language and with political correctness we can generate some insight into the stigma as we may have insight into the illness.

In the end once we get over problem of stigma, we can begin to explore what is on offer in the mental health system and once relations with your social worker improve they can navigate you through the system and life with the illness should begin to improve.

### **Navigating the Mental Health System**

The onset of schizophrenia is a bewildering experience for service users and families. The mental health system is complex and can be confusing, especially to those who are new to it. A good social worker will take the reins and help service users navigate their way through. What follows are some universals about social workers helping people with mental health problems as they relate to my own experiences and some reflection on how explaining things can be improved.

Social workers have a vital role to play in explaining and demystifying mental health to family and friends of the people they are working with. I recall the conversation with my social worker.

The first thing to do was as my social worker said was that with service users and families is to reassure, they are not 'insane.' This was a good point but explaining it runs up against some problems.

These include the negative media image and use of all the derogatory labels identifying people with schizophrenia. These can be challenged so far. The social worker was very articulate and had the knowledge to explain it in spite of the stigma being so prevalent.

We need to weight up the professional image of a social worker, examples of positive media images, and political correctness to effectively challenge the stigma. It is underlined by the existence of charities like MIND and RETHINK which help people with me. The social worker needs to know the right things to say and mine was very good.

Then she said it was just prejudice and ignorance. If we are ignorant of something will prejudice this according to how it looks. This was actually touches on a famous quote from William Hazlitt which says the same.

Once we have got rid of the stigma It was necessary to explain the system and how it works, to explain what it is rather than what it isn't. The mental health system is complex and can be confusing, especially to those who are new to it. A good social worker will take the reins and help service users navigate their way through it.

The first thing that comes to mind is to explain words like delusions and hallucinations. These notions are difficult, but I understood them when defined by the social worker. Delusions are beliefs that are not real but believed to be true by the person thinking them. Hallucination involve hearing or seeing things no one else can. Often the beliefs are paranoid which thoughts which are suspicious of other people. They can be looked up in the Dictionary.

Another important question was what is a mental hospital and what does it do? It was explained first that the delusions and hallucinations are symptoms of an illness called schizophrenia. This was a mental illness rather than a psychical illness affecting the mind not the body. Yet paradoxically the causes were physical and in the brain. These were the result of a chemical imbalance which can be corrected with medication ie drugs designed to change the chemistry. A mental hospital is a facility for helping you get better when there is something wrong with your mind.

And how does it work? This question was best answered by seeing a hospital ward first hand and by having a social worker to explain all the different therapies and approaches to mental illness. This will help also explain thing clearer and will further explain the idea of a mental hospital.

We have already noted the role of medication but that is just one approach to dealing with schizophrenia. Again it needs explaining the other notions involved which are just as difficult. After the medication was ineffective, I was guided through the other therapies by suggestions from my social worker.

Alternative treatments include cognitive behavioural therapy, and it was necessary to explain what is meant by 'insight.' By this it was explained the service user will know how the delusions look to other people and the test is whether you can see it the same way yourself. That explained it very well.

Another theory is that schizophrenia is stress induced and this can be understood better by using layman's terms being driven round the bend, driven round the twist and driven mad. This taps into what people already know and again it will make sense to them. The answer here was to use distraction and confrontation to overcome the fear and though this is easier said than done it can be helped by supported graded exposure.

I was interested to find another talking treatment called Compassion focuses therapy and it was necessary to explain what compassion is and how it can help. My social worker said it was about sensitivity to suffering and motivated to do something about it. Being compassionate can help soothe the fear and emotional pain in schizophrenia.

Some people get fed up of conventional medicine when it doesn't work and look for homeopathy remedies instead. For schizophrenia this is Wolfsbane and for depression there is St John's wort. Other treatments I have had was an Indian head massage and Gluten Free Bread.

When in hospital the staff treat the whole person not just the paranoid thoughts they are having. Maslow's hierarchy can be used to describe this well. Starting from being fed and sheltered there which allows some confrontation with the fear. Then the emotional pain can be talked over and with some positive reinforcement from the family and social workers. We can feel like our old self again. In hospital we are also free of stigma which reduces self-esteem.

### **Discharged**

When stabilised on medication it means leaving hospital. It has been explained how the system of secondary care works. Families and service users will need to know what sheltered accommodation and day centres are and how they work.

In sheltered accommodation many of the services provided in hospital will be continued. Service users will still need prompting before they will wash and eat and sheltered accommodation is just that as it is free from stigma. Also, the job description was to provide emotional support for people with mental health problems and the staff are also free to support you with being lively, active in life or simply just to have a soothing chat. They can spend much time with you socially.

Crucially Schizophrenia is prone to relapse, so the condition needs monitoring hence sheltered accommodation. Yet another danger arises here in that doing nothing is boring and being bored is stressful. There is a need to keep active and this can be answered by going to a day centre where there are educational courses on offer. They are also good for meeting new people other than the ones you live with. This could keep you out of hospital.

In addition, all this provides a 24/7 social contact continuing from what they have seen to be working in hospital. It will have ways of making emotional contact when we most needed or by keeping busy so life will be less stressful. This might help avoid going into a crisis again.

### **Biosocial Model**

Psychiatry can reduce mental poor health to a medical model without looking at the social determinants and individual in context. Social workers are an important bridge between these two worlds helping to adopt strategies to reduce stress.

Life's stresses as we have seen can drive you mad and you have social needs to reduce stress as by emotional support living safely in a project. There are other ways to calm down and stop being depressed by keeping busy. It needs treating socially as well as medically to cure the stress induced symptoms. Here day centres can help by teaching relaxation and self-growth techniques, so we feel better about life.

The key point here is that having made new friends you can enjoy all the things in life ordinary people do like food, travel or shopping with anonymity and free of stigma. This freedom is the best way of reducing stress. The outcome is that life with schizophrenia can be very much more liveable with the support of a social worker despite the initial reactions of despair.

### **Conversations with My Social Worker**

I could see social workers were very caring and want the best for us. They are dedicated to their job and the caring side comes across very well. This was an important first impression and really struck me. The notion of a caring profession ethic hit me here and I knew the social worker was someone I could trust. Despite stigma I felt I could confide in my social worker in a way I never could with my family, and they were good at inspiring the trust in them this required. I don't let my family know how serious the illness gets in case they worry but without family support here the social workers help is vital. This was vital to monitoring but also accessing support and care.

It gives you a chance to talk over your problems with someone qualified to deal with them. This is more important than talking to a project worker. So what do you talk about? There are two topics to do with the

twin roles of the social worker which are to monitor the condition and provide care and support. These were the main subject matter for conversation.

I see my social worker once a month and find the contact very valuable. As they are there to monitor you condition and provide care and support It was nice to see the social worker as they were nice people and had good conversation skills. I say I go up and down with the illness. This needs mays of monitoring it. They can empathize and sympathise with what you are going through, and you can share your problems with someone else, you are not on your own with them. The chat with them is soothing. I don't need my family with me to talk to them which was always the case with seeing a psychiatrist.

Having a chat with them is emotionally supportive and therapeutic. I found the talking emotionally deep and cheered me up. They know about the suffering involved despite its otherness in the job they have. Once they know what you are going through, they can give you some compassion.

Talking about and monitoring the symptoms was very assuring when I was worried about things and my social worker told me everything will be alright. I had enough insight to know if needed to be in hospital they could look at that too to see if I did.

It was reassuring that they can monitor your medication if you are feeling unwell. I responded well to changes in meds, but they are also very clued up by the latest talking treatments. Any insight can be discussed and reminded about which is useful.

And if I needed to talk to them in between episodes I knew they are just at the end of the phone. If you panic when getting some symptoms, they will know the right things to say to calm you down. They will do everything they can to keep you out of hospital.

They can give you positive reinforcement versus the voices and delusions despite 9/11 and emphasise they know you and that you are still a good person. They said this with some authority and had this to rely on when the voices were at their most critical. The longer they were assigned to you the more this impression was reinforced.

They listen to what you say. You go up and down with this illness and how you cope with it. So, when each is not visible they can know how to help you describe the difficult times, even if this is difficult to get across without seeing it first-hand. There are many factors involved here.

They are qualified to talk about the illness head on in a way project staff can only distract you. They have to be thorough at discussing everything. They like to know how you are coping with life and can discuss that too, but this can be a very mixed picture.

They introduced me to safe place imagery, and we talked about being supportive in my own environment. I could pick their brains about this. There was a need to feel safe in your own home and they were able to help with this by being there with me. The feeling of being safe lasted some time until the paranoia came back.

It has involved getting across what happens during a whole day or week. This got repetitive but it allows the social worker to get a whole picture of things. Day to day life is not just feeling ill but filling in the time too. You can look at what coping strategies you have and how well they are working.



An example is how motivated you are to look after yourself and the social worker will notice this. I often get sick of housework and like the exercise it is arduous, so it is not a good way of keeping busy. You need to talk this through in the context of what things do motivate you and it will help you get through with it.

Often when you talk through what is happening in your life and weigh it all up your social worker can emphasize it is not all bad. This stops low mood and any suicidal thoughts once you realise this. It is too easy to focus on the negative.

They can talk about the good phases in life, and this really cheers me up. They can really bring home what these are like and the different effects it has on you. This will stop you worrying all the time and with feeling sick of things. Talking it through makes things not as bad as they appear, and this can get you motivated.

They treat the whole person not just the symptoms and the conversations about the social side of life are very valuable especially when you are frightened and depressed this can talk you round. The talk induces a very pleasurable feeling.

How are you finding the exercise is another important question? It is physically taxing, and I hate it but it does for breaking the day up and getting out the house. This needs to be done each day as the day centre is only once or twice a week. Shopping and food out can help here too. Other than that, there are not a lot of options for things to do.

How do you feel about social inclusion? Day centres: do they makes a difference? You may need to make contact outside the system which is difficult because of the stigma. I joined an archery club and further education college course which I liked more than the day centre.

Being lazy and unmotivated is dangerous for keeping busy and this should be monitored closely. Social workers should pressure for going to a day centre here. This only worked so far for me, and I needed to get involved with something else which I really enjoyed a lot more. Here archery was a solution.

They encouraged me to stick with going out even if it was frightening at first. Once I got to the day centre, I started to relax. It was only the bus journey I didn't cope with. A volunteer driver was put in place.

How helpful it is going at the day centre? Keeping busy in the right environment stops you being lazy. It is good to have something to look forward to here though on the other hand sometimes it doesn't make much difference the rest of the time.

They will ask if we have made new friends and how we are coping on the courses. These are all the things that help with the illness, but you can still end up very isolated. You might have to look elsewhere to meet new people.

The social worker will look at mood and ask on a scale of one to ten what it is like when feeling low? How long does it last and how often does it happen? Do you get suicidal thoughts and how often? Here I cannot rely on my family for support with so having a social worker is vital for emotional support. I did a spread sheet for the frequency of all this, and it made me realise there were more good times than bad.

How are you coping with the stigma? You can still get frightened but if you act normal no one can find out. I had to avoid being seen by the neighbours, but the social worker will have to keep an eye on this. Stigma is not omnipresent, and I told the people at the archery club I was schizophrenic, and they knew what it was.

If you are ok with things, they will tolerate a certain amount of drinking. This helps pass the time sometimes, so you are not going from terror to boredom all the time. It will calm you down during the terror phases and cheer you up when bored. It is too easy to get dependent on this as often it is the only answer.

After chatting with the social worker the good feeling lasts and during the next episode it gives you something to look forward to. Finally, when moving out of sheltered accommodation this contact with them became very important.

### **Conclusion**

After the onset of my illness, it became crucial to be introduced to the mental health system and how it works. Once there the support I have had from the mental health system has worked very well for me and has improved my quality of life in many ways. Once stabilised on medication I was able to leave hospital and enjoy better opportunities for socialising and keeping busy. The conversations I had with my social workers was a key element in all this and eventually the system allowed enough support to live independently again. This has greatly improved my mental health.