

Short Paper

Locked in a Room

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In 2005 my illness relapsed and I began to feel like I had caused 9/11. I was being spied on by the neighbours and other people outside and that meant not going out. I spent ten years just being in a room.

My hideaway was not completely a refuge as I began to be criticised by voices talking about 9/11 much of the time. I felt the voices were watching and spying on me in the same way I felt the neighbours were.

I had to be very careful what I was thinking and not let my thoughts drift on the fact of 9/11 but with that paranoia this was going to be inevitable. Yet there were possibilities here which have worked for me over the years though the risk has always been there.

One of the coping strategies with schizophrenia is that you can distract yourself. This doesn't get rid of the thought but allows the mind to notice it less and at the same time notice other things.

This keeps the thought at the back of the mind but is manageable to the point you can pass the time doing other things and being confined in a room there is a need to do this.

All the same I felt I was in much danger and I had to make sure I wasn't thinking about my problem of 9/11. That meant immersing myself in some activity or conversation that put these thoughts nearly completely out of my mind.

I was fortunate here that my psychology just regarded these thoughts as system overload and would be stored in the subconscious. That helped make the confinement less intense.

All the same I could be so lost in experience that I forget to self-remember and would be totally absorbed in whatever I was thinking and doing. The hope was I could get through life like this and being able to ignore the problem of responsible for 9/11.

Every now again the thought comes through to the fore and this is where the problems of fear and confinement begin to occur. Dealing with this makes life with schizophrenia much more difficult.

My initial response was to try to sleep through all of this and with the sedatives in the medication this was possible. Over the years the more sleep you get the more you need and this ended being for fourteen hours a day.

I could stay in bed just dosing for hours and the comfort blanket proved very effective with the anxiety. This could be combined with listening to some distracting music but the problem was you cannot stay prone forever.

Alternately having dreamed about the catastrophe of 9/11 I could wake up in fear to the point of being frozen. This meant I couldn't get help from the project staff until it wore off.

This was a curious experience because I was so drained emotionally that the only answer was to go back to sleep but having already slept so long taking more tablets wouldn't knock you out again.

Being too exhausted emotionally with the pain of thinking I had killed all those people meant that I was stuck being prone and in bed. This was combined with the increased adrenalin meant your body's system was also belting round at a hundred miles an hour until it started to wear off again.

These feelings of fear can sap your strength and it was necessary to make staff contact for support until you got to the point of being functional again. Thankfully these points of nightmare induced paralysis only happened periodically and so I was able to keep out of hospital.

Once awake I was in desperate need for support and distraction and could lose myself in conversation over a cup of coffee with both staff and other residents. Again this passed the time and helped with getting through each day.

That meant having a mental hand to hold onto even when alone with the symptoms. I had enough insight to know the symptoms would pass and life would return to its normal emotional and social level. Sadly this insight was not present all the time.

It was necessary to try to think of things that might ease the restrictions and I decided to enjoy what was on offer which included alcohol and take away food. That allowed some source of therapy in the short time but with the food you can have too much of the same.

When I relapsed with my schizophrenia I was deprived of a lot of things that were therapeutic like not being able to go out for fresh air and exercise which was very unhealthy.

I did not have room for a tread mill and was asleep trying to get through it all which meant I was putting on lots of weight and not exercising. Over the years this problem was getting worse and worse as was the weight gain and I went up five stone in weight.

At the same time, I was not exercising as I was comfort eating a lot and having what I wanted. This has been a vital source of therapy but it had to end as I wasn't in danger of developing diabetes which was frightening as the schizophrenia.

I decided to try to eat more healthily and made sure I got a lot of vitamins which all helped keep my strength up. Under conditions of such adversity it is important to look after your physical health with a mental health problem.

The next obvious thing to try was to try homeopathic and aromatherapy oils like rock rose and lavender. This reduces the feelings of anxiety but didn't help with the higher levels of fear here. That left a lot of problems with boredom which like the anxiety was very stressful.

The answer here was to try to practice things like yoga or pilates which again were supposed to be relaxing. Again this helped occupy some of the time when the anxiety was less but wasn't a complete answer.

There was only so much I could do to calm down on my own and that put the emphasis on social contact and emotional support. Fortunately, when the relapse happened I was living in a mental health project and there were many advantages to this.

One was the homely environment of my own room which was well furnished and had much electronic media. Living without this the place would have been a dungeon but through this it felt more like home. Instead of a torture chamber the feeling of home was really quite soothing.

Also, instead of a prison cell with close confines I didn't end up keeping my door shut. Not doing this would have been isolating and keeping it open meant I could walk into other residents' rooms. It created a sense of freedom even though I didn't leave the grounds of the project.

The strength of being in sheltered accommodation as compared to being in hospital was that it was more homely and friendly. It felt less like being in an institution and there were longstanding friendships which with the relapse became important to managing the symptoms.

I had to get used to things and that meant adapting to staying in doors. Overtime that adaption and putting up with things became increasingly more difficult yet I felt I had no choice so I had to put up with it.

In a way I was very grateful for the confinement because I believed it was keeping me safe from punishment for 9/11. This thought occurred as I was being labelled schizophrenic I thought it would stop the surveillance from the neighbours who might be passing information back to the CIA as they would just think I was mad.

Trapped in my room was an overstatement as I was not on my own. The project was a safe place to be confined in and there was therapy up to a point. Life still had to begin again and that meant making one from being indoors.

With the professional support from the project staff I had the strength to eat keep clean, cook and do the housework. Some of my basic needs were being met but living like this was still very restrictive.

So the project was a refuge in a lot of ways and instead of trapped in a room I lived with other people with a shared corridor. I could keep my door open and that gave a sense of space. This would not be possible with independent living.

I was also not alone with my problems and had friends and staff in the project which gave the place a nice friendly atmosphere. I began to feel like home which again was better to try to deal with things independently.

I began to feel like I was living in my safe place and that helped calm my symptoms down so I was a bit more functional. Without all this I might have been moved to a different project and that sense of safety would have gone.

All the same that sense of safety kept me housebound as I was more capable of dealing with things inside than going out.

The downside was that it was still restrictive with not being able to go out to do the food shopping, exercise or go on holiday and all the other things people normally enjoy in life.

One thing in particular with not getting out was living without the sun as I didn't dare open the window blinds in case anyone noticed me from the outside. Ten years without sunshine was very difficult.

It was important not to give up hope particularly as other people had recovered or endured the schizophrenia for similarly long lengths of time. One thing stuck in my mind was the drug clozapine which was a medical advance and maybe a new drug would end the confinement.

Once again there was a need to adapt to how long the symptoms were going on for and often there seemed little hope for recovery and that the confinement would never end.

As time went on the experience of confinement was all I could remember and that was really quite depressing. It had been so long that I had forgotten to remember what it was like getting out and about. I was locked in a room for ten years.

That restriction had an impact on my mood and staying in a room intensified the symptoms by concentrating my mind on them even though as I said I could keep my door open.

That intensified, longer term and increased feeling of confinement was still balanced by the therapy of being safe and friendly. Then even with the increased feelings of fear and more focused symptoms the project helped keep me out of hospital.

I was also lucky in this respect that I was still able to look after myself and wasn't isolating myself socially, which again kept me out of hospital. Living alone this story would have been different.

Outside I was thinking people would be reading my mind about 9/11 and passing information back to the CIA, so with staying indoors I was safe from this. I thought they could only read my mind if they caught sight of me and this thought was often calming.

Staying in the project stabilised my symptoms as the levels of stress were somewhat alleviated. Going out in contrast meant the possibility of a relapse and perhaps another nervous breakdown.

Long Term Problems.

Living indoors also meant there had to be some distraction to take your mind off the symptoms and without this you are more subject to feelings of being terrified by the paranoia. There has to be something to stop the suffering but in the long term the possibilities here become less effective.

When the symptoms first started It was more possible to distract myself with movies and music. At the start this was helpful as I had things on disc that reminded of the time before the illness.

The problem here was that over the years these memories were beginning to be fade and the only thing than came to replace them were experiences of being ill and much therapy was lost.

Another thing that was happening simultaneously concerned the limited number of things I could watch and listen to. I began to get sick of the repetition and eventually got tired of all the media I had collected. This was also serious because it was one main way of passing the time.

I could only watch things I had already seen as I knew what was in them. I began to think I was being talked about it the media and that cut me off from other sources like television, radio and having anything new to listen to or watch on disc.

Another answer was to take up writing which provided something meaningful to do indoors even though it is a lot of work. The problem here was that you cannot spend all your life working as this is stressful too. That still left much time unoccupied.

I had to find something else to fill the day with and one answer here was to use the internet. Just as I had friends to talk to both in the project I found I could meet friends on line and this too acted as a source of strength.

All the same I found there was a limited number of things I could talk about to my friends as we had all had different interests and past life experiences. This took some time as I knew a lot of people at the project and some variety in meeting new people was helpful. Not having normal lives limited the conversation.

Still, we could always talk about the illness though could not do this all the time as that focus could be depressing. One of the benefits of sheltered accommodation as opposed to living by yourself is that you rely on the fact you are not the only one going through difficult symptoms. Again this only helps so far.

That put a lot of emphasis on the staff for emotional and social support but having ten people to look after and having lots of office work in their job again this kind of help was again limited.

I still had frequent visits from my family which was very helpful with my mood, particularly when I occasionally saw my nieces and nephews. I could also talk them once a day over the phone. That still left a big social gap in my life at other times.

Another problem here was a I could not go or stay at my parents' house and go back to the village I had grown up in. Without this I felt more uprooted and cast adrift. These feelings of home were stronger than the mental health project. Again I needed to get out.

So, the days became very repetitive and monotonous as all the usual distractions wore off leaving me more prone to the illness. The downside was also as with the more moderate symptoms I was left time on my hand and life became quite stressful.

Confronting the Fear

In the long-term staying indoors with less distraction and a mind with prolonged concentration on the delusion and voices was getting very frightening. I began to realise that handling these terror episodes was possible so it might be an opportunity for getting out and about. Other factors also had a push and pull effect on the need to get out of the confines of the project.

Things were getting worse as time went on and over the years the possibility of therapies and distractions when staying inside the project were running out. Even my writing just turned out to be a job not a peak experience.

It was either spend your whole life in hiding or trying to confront the danger of being reported to the CIA. I thought even though I might be killed doing this I would at least start enjoying life again before this punishment happened. I began to feel they would get me eventually anyway so there was nothing else to lose.

The other thought here concerned the stress of going out and that over the years nothing was changing. I began to realise that if I did nothing about it the whole life will just have been wasted. That meant the risk of snapping again making any recovery more difficult but if I didn't do anything about it nothing was going to change.

It was like being in a war where you have to dice with death daily. There is no choice with being blown up or shot you have to have the courage to get through it. These were the levels of fear involved with confronting the paranoia about the CIA but with some insight there was the possibility you might survive.

I was also getting dependant on the place I was living in and was becoming institutionalised. That created more fear when trying to go out and to do this I had to gradually overcome this too in addition to the other problems.

The answer was having help from a support worker so that I had someone else to rely on when trying to go out. The problem then became that this created a new form of dependency relying on the helper so eventually had to do this on my own.

I had learned to live for so long doing without the things which many people to enjoy themselves that I got so used to it. I barely remembered what it was like to enjoy the material side again. This was another motivational factor for getting out.

Having locked in my room for ten years I began to feel I was getting older and that my whole life was passing me by. This was scary and depressing. Again something had to be done.

Eventually I was so frightened by the illness all I could think of was the fear and this did put me into shock. I was worried about how things might deteriorate I became isolated and withdrawn. Getting out to distract me from the voices seemed very difficult.

I think family was the key factor in helping me cope here and with staying out of hospital at this point. Being on my own in a mental health project with just friends around me meant I would not have had the strength to deal with the fear. This again would have felt more isolating and might again mean being back on a hospital ward which would have just made things worse.

Something had to be done to stop the confines concentrating my mind on the paranoid thoughts. More than this with getting older I had to find something enjoyable in my life which was rapidly passing me by. This could soothe the fear and allow more possibility of distraction through going out. That meant biting the bullet and try and do this?

Getting out

What became apparent was that there was more therapy when out and about than staying at home. So instead of the increased fear there was increased therapy and a natural transition from one to the other.

In some ways this was because I had a support worker. There was someone to come with me and I started to visit places that I had associated with safety before the illness. I could replace the new safe places with the feeling of being safe in my room.

Getting over the increased fear of being out meant that a Valium was needed, at first, to take the plunge with this. Taking a few deep breaths wasn't going to be enough for that first step. Once I got used to being out, I could eventually do this without the nerve tablets.

That first step was particularly significant as I had forgotten the feelings on the sunshine, the sense of space and the fresh air. The initial impact of this was overpowering and provided a tremendous sense of pleasure and relief.

I began to enjoy the exercise again and the endorphins helped with my mood. This was very important to me as the anti-depressants didn't work and I was also able to lose a lot of weight.

That weight loss was very important because as I have mentioned I had a diabetes scare in which you can lose your arms and legs. That was something like what I thought the CIA were going to do to me anyway and that was a tremendous push for getting out again. The result was I lost three and a half stone in weight.

Getting out meant I rediscovered a lot of things in life I had forgotten about, like shopping and eating out, and this helped with mood. Eventually I began to experience pleasure and enjoyment instead of just the fear.

Looking at the shops I began to feel stimulated in ways that de-stultified the mind, which is what had happened to it when locked in doors: being in one room for so long wasn't exercising the brain and I spent too much time just vegetating.

In the end, I felt life was not going to be passing me by. That realisation was very important because again it was suggesting a better future and as I said the anti-depressants were not effective in my case.

Conclusion

I think the most severe symptoms of schizophrenia can be dealt with providing the fear is confronted with proper levels of support. Hiding away from it is too easy and if something is not done straightaway the chance of getting life back to normal are very much more difficult.

The psychological barriers to doing this are very strong and it needs someone to rely on to help you take that first step and then support you as things progress. This is a process of graded exposure which is beyond the scope of this article. Yet the therapeutic value of getting out described here is very important to understand.

In my case I had to realise that my avoidance strategies were not working and that life was never going to change unless I did something about it. The only answer was to confront things head on and try to overcome them.

The key to all this is to inspire some hope within the individual that this sort of thing is achievable even when it seems so difficult. It is important to realise that they are not alone in the attempt to get things back to normal.

That hope will grow and become more evident once we start to practice these things. We can formulate the outcome that we can get back to living a normal life. That therapy should be the goal for mental health service users.