

Original Paper

Living with the Tactile Hallucinations of Being in Pain and the Intensive Therapy Unit

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My schizophrenia started out with hearing voices and delusions about being responsible for 9/11. These where both terrifying and emotionally painful and just when I felt things couldn't get any worse with the illness I began to develop another symptom: pain hallucinations. My original symptoms were classified as particularly severe by my psychiatrist but I began to have something that was even worse.

The fear from the schizophrenia was bad enough but fortunately it was rarely combined with the pain so I was not experiencing both at the same time. The problem was that I was getting fear some of the time and pain at other times. This meant the time I had to endure the illness had increased as I had more and more symptoms which meant I was ill most of the day.

One consequence of the increased suffering was that it may have affected my mood. So, fortunately I was living in sheltered accommodation. That meant having furnished my own room and having happy memories of socialising there made it therapeutic. This together with family support and being friendly with the staff as well as the other residents that I was saved from this. Having depression on top of the other symptoms would have made things even worse.

Gradually as the pain hallucinations became more frequent it began to take over my life with the illness. The only thing I could use to cope with the pain symptoms was to hang in there and wait until it passed. I used to tense up and tried to be prone to get a grip on myself by hanging in there until it wore off. Otherwise I took my sedatives to get to sleep which avoided the pain.

As the episodes of pain increased, I began to live in fear of the next bout of pain. It was on my mind all the time and began to record its frequency to see if there were long enough gaps and to see if it was only happening a minority of the time. The longest phase in between episodes was fifteen days which inspired some hope. Yet eventually having jotted this down it revealed it me that was mainly happening once every three days. This again was frightening.

I began to be afraid of getting out and about as if the pain started I would need to get home and get back to sleep on the tablets. That thought kept me housebound as I wasn't prepared to take the risk. The only

way of doing this was to go with a relative who could drive me back once it started or to go somewhere where I had a short taxi ride back home. Most of the time I didn't dare do this and stayed at the mental health project I was in.

Not going out had consequences for the other delusional and hallucinatory symptoms as I used to enjoy this and it made life with the illness more bearable. Now there was less ways of finding an outlet when staying at home all the time. This was helped so far by having friends and staff at the project and talking to them was something of a distraction so this took the edge of the fear I had.

I was frightened by being responsible for 9/11 and the voices criticising me for it. Yet now I was getting even more fear added on when in between having pain episodes I was scared about the next bout of those symptoms. I needed a coping strategy as the talking only helped so far and had to find something around the house to take my mind off everything. Living inside the house was very restrictive and I had to adapt to not getting out as well as staying indoors all the time.

Staying indoors meant I could not go to my local mental health day centre. This meant there were no courses to do and I lost some social contact which used to act as a break from living at the project. Many of the other things I enjoyed doing liking going for a walk to get some sunshine and fresh air was no longer possible though this could be remedied by sitting in the garden at the project.

Also living in the project had another added benefit in that I wasn't completely locked away from everyone in a room on my own. I could keep my door open into the corridor of the project and other residents were doing the same. This created a group atmosphere and my mind was less concentrated than it might be by being confined in a small space. I could breathe more easily with the space and the people which was pleasurable even with the pain.

Other coping strategies like going shopping or to the cinema also had to be stopped. Again, there was a way round this as I could order DVDs off the internet and do my shopping online. This was also the only way of buying groceries. Otherwise some of the responsibility for this fell on my mother who was going to the local supermarket to charge up the gas and electric which was only way of doing this.

My father would also come to visit. Then I would buy a DVD and instead of going to the cinema and we would sit and watch it together. Again the family contact was very helpful in distracting me from the fear effects of the schizophrenia which meant some further release from it in between the episodes of pain. It was also necessary to keep busy as much as I could either by leisure activities or just by doing house work.

Once a week I had a get together with my friends and would order some take away food. It was necessary to treat yourself now and again in the midst of all the suffering. Then having a bottle of wine at these times made the meet up go with a bang. We had some music playing that we both liked and the conversation was very good and at these times I wasn't just distracted but cheered up.

Another casualty of the pain hallucinations was not being able to go on holiday. The only way this was possible was going with the staff on the annual resident's holiday where there was support. I didn't dare do this with my friend as it was a professional job to talk me round when I was really frightened. So, I

took the risk with the pain hallucination that the holiday was only for a week and I might escape it if I was lucky.

Going on holiday was very important for dealing with my mental health as it provided a break from living in the local area. The change of scenery was as they say as good as a rest so with holidays and I found it extremely relaxing. This had a stronger effect on keeping me calm and was more effective than going to my local health day centre. It also provided a break from the illness in which my schizophrenia was stress induced.

Ideally it would have been better to go away more often, and it was possible sometimes just to go with my friend. This wasn't always just local travel and it had been possible to contemplate going abroad which was much nicer and more therapeutic. The problem was that the voices, delusions and pain hallucinations might be all happening at the same time, although this rarely occurred. That would prompt a psychiatric emergency and it would be left up to my friend to deal with this.

Another problem with any travel was that if I was really ill it was more relaxing to be in my home environment which would have kept me calmer with the voices, delusions and the pain hallucinations. Being in a hotel or a villa would only make things worse and I couldn't multitask my brain by watching a movie while enduring the symptoms at the same time. I could bring movies on holiday but without being at home the distraction was lost.

Being at home did however have a twofold effect on my symptoms. First it was more therapeutic dealing with the ordinary schizophrenic symptoms like fear and to some extent the pain. Yet secondly at the same time being indoors concentrated my mind on what I was experiencing. This meant I was more distracted at home but suffering more at the same time. Eventually this trade off from being inside all the time began to make things worse.

Getting out meant the possibility of having other forms of distraction rather than sitting in the house. Yet it also ran the risk of what to do if anything went seriously wrong when out and about. In the end I decided to give this a try under great pressure from my friends and family as hiding away all day on my own didn't seem to be working with the fear I was living with.

There were dangers here as the fear became so frightening that I couldn't move and at other times I thought I was going to pass out. If I was away from the staff support at the project I wondered what would happen if I collapsed somewhere. The hope was that in a public place someone would call an ambulance but even so I didn't relish the thought of collapsing and going out with when this new prospect added to the fear.

The answer to this came with the putting in place of someone to go with me so if anything happened there would be an answer to this. I was provided with a nurse which was very reassuring as if the extra stress caused a relapse with the schizophrenia she would know what to do. The extra fear was only calmed so far as I was still frightened of the prospect of passing out even with the extra help.

As far as the ordinary schizophrenic symptoms were concerned getting out could be dealt with so far by taking deep breathes and using safe place imagery. This provided a way of getting back to the day centre

as these things were being practiced and taught so the extra fear could be dealt with. Again as the pain only happened now and again I could take the risk of spending a few hours at the day centre or out with the nurse.

Even if I wasn't ready to do this on my own it provided some time each week when I wasn't stuck at home with the symptoms. Then I came to realise that the fear could be dealt even with the impact of passing out. So there was more possibility of avoiding the extra worry this caused which might have triggered a relapse. This was a start but I still wondered what would happen in taking these risks if I got the voices, delusions and pain altogether.

It was now possible that at a day centre or out with a nurse that in a psychiatric emergency I could get help with it straight away. This provide some reassurance. Yet this was beside the point as the experience would still be traumatic. Again I was thinking it was better to stay at home as sooner or later this getting out and about would be asking for trouble.

All the same going out was having many beneficial consequences as once back at the project I felt refreshed and happier to be at home for the rest of the time. Again this was a therapeutic feeling and added to the other benefits of being at the project like the staff social contact, media distractions and having my friends around me. I felt more lively and the conversation improved and I started to enjoy the homely feeling more.

Getting out also has the added benefit of being able to do some exercise and physically I began to feel healthier. The two years of isolation being locked away with the pain symptoms meant I was getting very out of shape and my weight increased greatly. The exercise and a proper diet meant I only gradually felt better as it took a long time to get back to where I was with this as it is possible to get seriously out of practice very quickly.

Eventually the fear of passing out could be dealt with and I often didn't have the two problems of pain and fear together. That just left the pain on its own which was bad enough and I only felt marginally better with it even without the fear. Again I had to find a solution as it was not always possible to take my tablets and go to sleep due to the problem I had already been sleeping a long time in any case.

One other answer was to try and sleep as much as I could and the more sleep you get the more you need. The medication I was on had the strongest sedative and I ended up sleeping fourteen hours a day. Yet that still left plenty of time for getting the pain symptoms. Again this was physically unhealthy and despite the risks of going out I had to exercise and diet a lot to keep this under control.

I ended up thinking I had simply had to get through the rest of my life as the pain wasn't letting up. So I began to watch the days merging into each other and the seasons passing by. Again there was a need for some therapeutic activity as the problem was reaching suicidal levels. Then I was put on an anti-depressant which was not effective. I was never in danger from suicide as I couldn't cope with either the pain of it or what I was experiencing.

The activities when getting out and about were an effective way of passing the time as well. Yet although distracting the continuous bouts of pain began to be on my mind more and more. There was not a lot to

ease fearful thoughts as things got much harder to deal with. So, although I never sank into depression with them I was finding it was limiting my social contact which had to be cut short once the pain started. The point was to get back home as soon as I could once the pain started and the getting out either with a nurse or my family meant I could have a car ride home to do this. So I could still get out for the exercise and other activities but often this had to be cut short as well. Again this happened frequently enough to prevent a lot of this even though I wasn't going to pass out with the fear.

All the same the getting out and about was only for a few hours each week as the time available with the nurse was limited to only a few hours. That put a lot of responsibility for practicing doing with this on my family. I was able to go to my favourite places like the historic city centre of Durham and The Metro Centre Shopping Mall or out for exercise more but often I would still have to come back again as quickly as possible.

One outcome which was becoming apparent as the pain symptoms were getting worse was that I was getting highs and lows. I felt like things were nearing the end of the world at the low points of discomfort and then when they wore off I was getting feelings of exhilaration and gratitude that it had stopped. I was determined to live as much as possible in between as I was so relieved things had got back to normal. This now took my mind off any relapse.

When the fear was controlled and all the symptoms were not happening together I began to feel some confidence in doing this. So, it was possible to enjoy them as I knew I could always get back home. Yet at other times I was getting severely sick of being in pain and all I wanted to do was sleep. Going out meant that even if things were reaching crisis levels all I had to do was get back to the project and try and deal with it.

Eventually the more I was getting out the better I felt and I had some sense of freedom again as I was perceiving things were getting back to normal. I was experiencing that freedom in a number of ways by doing the things I liked the same way other people do. This included enjoying work like activities in addition to leisure opportunities by doing courses at my local day centre. Again this way a safe environment in case anything serious reoccurred.

Of course things were still a bit restricted as I couldn't get out on my own or just with my friends as I used to. Yet after two years of confinement in a room this didn't matter at first as they was such a strong sense of release. Eventually though this again began to seem a bit restricted as I wasn't free to do this very often but I put up with this for a long time as at first it didn't seem to matter. Just being out and about was such a big improvement that it was still very therapeutic.

The increased frequency of being away from home helped break the day up and eventually I was out nearly every day. That increased the number of activities I could do as I was getting sick of the same old media from staying in my room and helped improve my outlook on life. All the same this feeling of improvement would not last during a symptomatic phase with the pain as at those points it always seemed like the end of the world.

All this meant one minute I was happy and enjoying life and the next I was in terrible pain. Like a bipolar mood swing I was getting constant highs and lows so that life was full of ups and down. Next the experience of these had a tendency of levelling each other out up a point. The thought of relapse reduced the happy times even with the support I had. Then knowing I would get through the pain as by sleeping helped with the lows.

What I really wanted to do was to get back to some of things I had in life before the illness and that meant going to places like Archery and Gun club which were outside the system. Yet if anything happened that needed emergency support in these places, so that I might have to go back into hospital, there would be no help available. This problem meant the not going out was still a very confining situation.

Especially I wanted to go back into education which was the main interest I always had in life. Yet being in pain meant I couldn't get to a library or a classroom in case I needed the same immediate support. This would have been more distracting than doing information technology courses at a day centre and more enjoyable than just going shopping or watching a movie.

After a number of years, the novelty of being at the Mall and eating out began to wear off. So, I needed something more meaningful to occupy my time than just meeting up with friends and family. I was getting bored with life and certain other activities like holidays and cinema were not available as they meant being so far away from the help or were triggers for my psychoses.

One possibility was alcohol and I started to drink while inside the project and for a while was able to combine it with getting out and about. The drinking had to be kept in moderation as it can trigger a psychoses but for a while it did have the benefits of calming me down and cheering me up. I quickly developed a tolerance to it however so it had to be limited which again meant I could always rely on it.

All the same as the years went by and the pain symptoms were not easing up. As I said I was getting them at least once every three days and sometimes more often than that. I began to feel fatigued and going out wasn't helping as I was getting sick of it all. I Just wanted the symptoms to stop and looking ahead all I could see was more of the same. There seemed no possibility of a let up or a solution.

My life with the pain at this point began to seem hopeless as it seemed the pain was never going to go away. Now it was less that I had to get through life until the pain stopped and more that I had to get through life until I died. Thoughts of being suicidal began to occur more frequently. Then at one point I took three times the maximum dose of clozapine and another time I tried to get run over by jumping in front of a bus.

If I had been strong enough to commit suicide I would have been strong enough to deal with the pain as both things were about as severe. Yet thankfully me being too weak for this meant I was safe enough even with the severe symptoms. The best way of describing what happened with the pain is that I got through it willy nilly as I never built up the strength needed to adapt or deal with despite its frequency.

The pain was something I never was able to manage as it was so severe. I found the experience was so overwhelming there never really was a total coping strategy. Also with it being a hallucination meant that pain management classes provided by the national health service wouldn't have made any difference. So,

I had to find a way of dealing with it on my own but pain is something that is difficult to distract yourself from.

Hanging in there and knowing it would wear off was never a complete possibility even despite the hope learning this could have been done for getting through things with the hallucination. In pain is being subject to pain and there is no way of talking yourself round that it will eventually stop as what you are experiencing is so intense. I was always getting the full force of it. You could not simply endure it though this meant you still had to go through the episode.

Just as there was ways of coping with the pain directly it did help a little to be distracted by trying to refocus the mind on other things. Being in pain means the pain is all you can think about but I was also conscious of other things at the same time as I tried to think about something else. I often tried playing music to help with the experience and this took the edge off things so far.

Being under the comfort blanket was another strategy as well as being at home both of which were soothing. So, being in my own place meant I felt a bit stronger for dealing with it. This was effective only so far as I still had to put up with the symptoms. This again it did have the effect of easing the problem so far though this was also marginal given the extremities of what was happening.

Another possibility which was a bit more effective was reducing the tablet intake on a night and having some left over for during the day. I often tried to take my tablets at the point of the onset of the pain during the afternoon which was when the symptoms were most likely to occur. That would knock me out for a couple of hours though I had to wait for them to kick in and to put up with the side effects on top of the pain.

On an evening this was also possible but unless it was late at night it meant going to sleep a lot earlier which was not physically possible, especially if I had already been asleep during the afternoon. Yet at certain times this was also more difficult in that I hadn't been awake a long time during the day. So trying to get to sleep earlier both at night as well as an afternoon meant I ended up dosing instead of being asleep, still getting the pain.

Prolonged bouts of pain started to sap my strength and I looked gaunt, having sunken hollows in my cheeks. The pain was physically exhausting and my disturbed sleep patterns were adding to the problem. I began to look at my diet and eat more healthily and this meant that in between bouts of pain I could keep my strength up. Then even with frequent symptoms I had a way of keeping strong enough to help deal with it.

Another worry with the passing out and looking like I had malnutrition was that I might have ended up back in hospital. That was a frightening prospect as I would be less able to cope with it than being at home and I didn't want things to get worse than they already were. Fortunately this never happened as I never tried to disguise my symptoms and kept in close contact with the psychiatric help. They trusted me to deal with it on my own.

Moreover I was in frequent contact with my family and my mother was visiting me three times a week so they could see I was trying to confront the problem by going out and about and not staying in my room

all the time. They knew if things were getting so bad that I might pass out I had an emergency phone number to ring and trusted me to use this if it ever became necessary for an admission.

Also, the staff at the project were there forty hours a week and could keep an eye on me during the day. Again it was possible to rely on them for an outing in addition to the input of the nurse and my family. Although this contact was only for a short time as they were often so busy in the office it again this helped me be functional in the face of the illness. It also eased my families mind to have this support through this as I could rely on other sources of help.

All the same the psychiatrist wanted to see me at regular intervals to check on how I was coping and gradually my medication was being increased to find an answer to it all. I had another try with the clozapine which I had originally abandoned due to the side effects. This as I was willing to put up with even this if it had the impact of reducing the pain I was going through. Fortunately the side effects did not reoccur yet the best drug available didn't cure the problem.

It did occur to everybody that this pain might have been real and not just a tactile hallucination and throughout all of this I had frequent contact with my General Practitioner who prescribed pain killers. Again there were various things I could try and again I was prescribed a number of different things and the dosages of each began to increase. The physical health doctor did say to me to keep in touch with the psychiatrist about the problem.

Something that everyone was wondering about was that I had a car crash prior to my illness and that I had a bad case of whip lash. The pain form that was in the same place I was experiencing the pain hallucination and might have caused the onset of my illness with schizophrenia. This might have caused the hallucination in directly albeit in the same place as the pain and was looked at very closely by the doctors.

In addition to the pain killers I was being prescribed and these got more and more powerful I was also allowed to go for an Magnetic Resonance Imaging (MRI) and Electro Encephalograph (EEG) scan to see if they would shed any light on the problem. Again these came back as normal and eventually I ran out of the things that the physical health side of the equation had to offer. So, some hope was being lost here. Another prospect that might have happened was that they might have thought that I was being delusional about being in pain. So that getting home and getting to sleep were being caused by such a delusion and I wasn't in any danger going out. Even looking pale and withdrawn could have been brought on by such a delusion. Luckily what gave the lie to this was that what I was experiencing resulted in looking so physically gaunt that seemed to confirm it was a tactile hallucination.

Eventually after having tried a lot of psychiatric and possible physical remedies it was clear that conventional medicine was not enough. I was referred to an acupuncture clinic for some alternative treatment. I am able to give this part of my story a happy ending as after a number of weeks with the therapy, there began to be some improvement with the pain.

I stayed at the clinic as long as I could as at first I didn't know that after the five years of the symptom whether the initial improvement was just a flash in the pan. Yet as the weeks went by the pain symptoms

did not come back and I began to recover. Of course, I still had the other schizophrenic symptoms but the pain had gone. Eventually the weeks turned into months and still no pain.

When all the other medical possibilities had failed it was the alternative therapy that had worked and I knew if the pain symptoms ever relapsed I would know where to get help and treatment for them. That eventuality was very reassuring and I was able to relax in the face of any return to the problem and I knew that the pain had been solved once and for all. So I am able to my story a happy ending. Yet to get this this the pain in addition to my paranoia put me in hospital at one point when the extremes of not coping with both put me in the intensive therapy unit.

The Intensive Therapy Unit

One day on the ward a psychiatrist took once glance at me and put me on the intensive therapy unit. I wasn't looking well having few distractions when being so ill and I now had the opportunity for more one to one help. The doctor was correct in his assessment of the situation and although the symptoms were severe, as we shall see, it had not been clear that transferring onto the new ward would altogether help.

Intensive was the right word for the place as there was a lot of staff and few patients. In fact, three staff for four patients which is something that should be done on the usual ward but is not due to lack of resources. This is only done for the most ill patients, and it does provide something that is badly needed through crisis episodes, although it comes with a certain cost.

So, my first impressions were good as I though this is what I needed and into the bargain the ward was very newly built. The modern design looked very comfortable compared to the more utilitarian surrounding of the ward I had just left. Some hospitals environments I had been in were very antiquated and were like living in a slum, so the modern ward seemed very congenial.

Yet the first impressions were not to last as the ward was only designed to cater for a few people and was very small. Thus, it was not possible to breathe so easily given the close confines. That had an immediate impact on me as I found it a bit claustrophobic. We are all crammed in like sheep with four patients and three staff huddled together in such a small room.

Then another problem became apparent as the close confines came to concentrate my mind on the problems and this made them worse. Having already been ill enough to be put on the ward the symptoms started to deteriorate and became particularly severe. Eventually the ward environment was able to help so far but initially it made the psychoses worse.

The stress of being locked in added to the stress of being delusional about being responsible for 9/11 and made together this made the symptoms worse. Especially the voices became more punishing and the whole thing deteriorated and became particularly severe. The increased stress of this began to perpetuate the crisis symptoms though de-stressing by offloading and talking things through with the nurses helped take the edge off this.

Underlining all this was that my consultant was very worried about me as I already had severe symptoms when being in the usual ward, such as when I was screaming the place down and he was called out during the night. On the intensive ward he came down after work to see how I was as I think he was worried about a recurrence of this by being admitted to the intensive unit.

Next being prone on my bed in there and too frightened to move very much I started to tear at my ears trying to stop the voices. Doing this my ears started to bleed all over the covers but fortunately this didn't do any lasting damage then some of the symptoms got back to normal most of the time. What was worrying the doctors that despite some improvement in between, such crisis episodes were that they kept happening.

The intensive unit had its own psychiatrist and after having observed my most severe symptoms he recommended a change in medication. I was put on a drug called Zotepine which proved ineffective as an outright cure, but the way things were going I was willing to give it a try. Some trial and error maybe required for treating schizophrenia and it might take several changes before they find the drug.

Indeed, one of the advantages of the intensive therapy unit is that it has its own dedicated psychiatrist, and you are able to get a second opinion on the antipsychotic meds. There are all things they prefer as most effective and things they won't touch so having the doctors confer bring more knowledge into the equation. Two heads were better than one in this situation.

Having two doctors in agreement about the new medication was very reassuring when I first started to take it but the problem with schizophrenia is that it is treatment resistant whatever drug is used. Having tried a few medications already I was stabilised on the new drugs, but things were still very difficult. This in comparison with the other talking therapies offered help the condition and I was eventually discharged. All the same the confines still had a bad consequence that being more focused on the symptoms my fear and stress levels began to increase and I largely had to manage them on my own. This was in turn was helped by the increased contact with the nursing staff, but this only went so far. Experiencing fear at these levels required a benzo-diazepine but this is not always done due to its addictive quality and in my case was not effective anyway.

The one-to-one contact was a distraction so far as there was good conversation it meant I could be calmer which allowed some respite with the illness. The care was soothing, and this helped calm my nerves a bit and as the fear decreased for a while I began to relax. This made up for the initial feelings of confinement but as time went on these feelings quickly became worse.

This nursing contact also helped with building some strength emotionally as the voices started to criticise again. It also allowed me to cope with the fear of being delusional about 9/11 and the thought I was going to be punished for it. Yet all the same as the longer episodes began to reoccur, again they were worsened by the confines things so remained severe, more so than being on the usual ward.

I was so caught up with thinking about 9/11 and the voices criticising me for that I was completely focused on it and no activity or conversation was going to get me thinking about something else. At

certain points the ward staff were able to talk me round but once the delusions got a hold on me this was not always possible. Displaying a caring approach was not enough to get these thoughts out of your head. Another possibility that arose from the constant nursing contact was the possibility that they were there to reinforce any insight I might have had particularly during the worse times. Again, this provided some rest during the milder phases of the illness but there is only so much insight you can have and during crisis episodes this was not effective.

Other strategies were possible that had a calming effective and could be used within the confines of the intensive ward. I was able to being in a portable computer games machine, portable dvd player for movies and music and had an internet connection on my phone in there. This worked so far during the milder phases of anxiety, yet it wasn't like watching them at home which was more relaxing.

The problem here at times was that when hearing voices, it was difficult to concentrate on the electronic media, as my mind was often focused so much on the voice and the delusional thoughts at the same time. At other times though this was possible when hearing the voices without the paranoia so that as I could listen to voices in the movies and music. This had a way of capturing my attention and had a way of bringing the fear levels down although only so far.

The phone came in handy in another way as I could ring my family during the crisis times, and this proved more emotionally supportive than talking to the staff on the ward. I had more trust in my family than the ward staff and I found the loving emotional support more soothing of the fear than talking to the nurses. Fortunately, I wasn't paranoid about both the staff and my family which would have cut me off from help completely.

This was reinforced by daily visits from my family and the caring face-to-face contact proved very comforting and reassuring. The family conversation was again naturally better than talking with the nurses while talking to them was very good in developing insight. They were able to reassure me what I was thinking was not real. I was sometimes able to trust them in this more than a staff member.

The daily contact was very important as it provided a kind of break from the institutional environment of the ward. It gave me a chance for real family/affiliative contact which the hospital tries to provide. This atmosphere had more chance with the increased social contact of the intensive ward but was still much less effective than actual family contact. Yet the two together was more beneficial.

On a usual ward the patients often experience a lack of social interaction as there are not enough staff to engage with you one to one. People are being left to be wrapped up in their problems and often are just staring into space. This must be avoided on an intensive unit as the symptoms are more severe and people cannot just be left to experience them.

Also on a usual ward engaging in activities can cure this up to a point as they will feel more motivated. So they are more likely to develop social relations and chat when back on the ward. Then this should lead to taking an interest in life again and the ability to be further stimulated by watching the television. Yet this option is not always available as many schizophrenics are paranoid they are being talked about on the airwaves and have to avoid the day room.

On the intensive ward though you are trapped in with the television and the only escape was to stay on your bed and drown out the sound with headphones and a Walkman. This problem however was quite isolating with the symptoms and cut you off from conversation with the nurses. Furthermore, you cannot sit all day listening to music and you still need some face-to-face contact.

This can be difficult if the staff on the intensive ward need to observe you and sometimes there is a need for constant observation if you are at risk of self-harm or suicide. The problem is that being exposed to a television through this can be terrifying to the point of traumatic given the scale of the terror. In my case I imagined that might thoughts about being responsible for 9/11 were being broadcast nationwide and the CIA were going to find out and punish me.

There is also a need to keep busy but on ITU there was little to do and talking all day was not possible. On the usual ward interesting activities were organised which were stimulating and enjoyable. Being on the lock up ward there was nothing to do and being bored became a major problem. This was necessary to passing the time which seemed to drag and made you more prone to listening to the voices.

Conversation with the other patients was also difficult who were too ill to talk. So when the symptoms were often bad it meant that the television could not be concentrated on or enjoyed as people were slowly losing their interest in life. Again, this put the emphasis on contact with the nursing staff who were trying to get you motivated once again. This was possible so far even on ITU and then the television started to come into its own again.

Being in so long started to take its toll especially as the feelings and awareness of the confinement became more and more acute. They were much worse than the usual ward. This was a depressing feeling and thinking to yourself that you have to put up with things because of the need for special help was not always effective. It is important to be discharged back onto the usual ward as quickly as possible.

You do get your own room on the intensive ward, but it was too small to spend much time in there. There was also nowhere to sit and no windows to create a feeling of more space. Yet you will need to get away from a place where people are getting really ill. Sometimes with schizophrenia you have to be on your own, but the confines of the bedroom made things more intense so they was much possibility of the symptoms getting worse with doing this.

There was a need to be on your own as in the usual ward which had separate bedrooms with windows overlooking the natural surroundings of the forest. This meant the nature was calming and gives you time to think through your problems. This was not possible on an intensive therapy unit and any possibility for reflection like this has to come through talking things with the nurses though. It was helped so far by having time to spend with you they will get to know your problems very well.

Often despite the emphasis on conversation about things wasn't going to work as I didn't feel like talking going through my problems. This was difficult because the delusion is so frightening, and it is hard to try and forget about it. It might have also been the case as is common with schizophrenia that the neighbours are spying on you and in my case might be passing information back to the CIA. It was often possible the nurses were doing the same which prevented social contact.

All the same at the milder levels of anxiety and during periods of insight it was lovely to have a chat. At times like that the distraction this is designed to produce meant you could off load some of the pressure you are under with schizophrenia. This reduced some of the intensity in there. Then the more you got to know the nurses the more therapeutic the talking was, and it was always good to meet new people who had such good social skills.

When really traumatised me is all you can think about is the mind numbing fear. Then being on a normal ward or locked up in intensive therapy isn't going to make any difference as you are so overtaken by the illness. So having a few nurses around you to bring you back to reality isn't going to work. This is just with the worse experiences which are so particularly severe. Yet they are not common to everyone and with lesser levels of fear being confined in there can be good and bad.

As things improved through socialising and conversation the symptoms hadn't deteriorated. Then I became dependant on the nursing contact for distraction and calming down. so i didn't know how I would cope without it when discharged off the intensive ward. yet sooner or later I had to take the plunge. I had become a bit stronger during the milder anxiety phases but was still worried by the times of crisis when there would be no proper support as when locked in.

Being let out still meant there were other things I could rely on to help with the feelings of dependency, created by having been locked in there and so reliant on the staff. The need for reliance produced by the severe symptoms was helped as they were not required all the time. I was still able to have conversations with staff and family, via mobile phones, even during the crisis times as well as with other patients during the milder phases of anxiety. This eased the need for intensive one to one help and my anxieties about this were slowly eased.

Being on a hospital ward is not a natural environment and is just a place to stay until you start feeling better, much like a stay in a general hospital when there is something physically wrong with you. What helps you get through it is spending time off the ward doing things you normally do. So getting back into the institution is much more bearable. The problem when being on a locked ward means there is no let up from the sterile hospital environment until you are let out.

When let out of the ward for the first time I could smell the sense of freedom. This was a good feeling and helped improved my mood as being locked in so long it started to get a bit depressing. This especially after the times when the confinement was making things worse. That helped cheer me up during the discharge and I began to enjoy the activities the hospital had to offer on the usual ward.

The sense of freedom was beneficial in another way as been back on the ward there was much more space as it was designed to cater for thirty people compared to the four on the intensive unit. I could breathe more easily, and the day room seemed very spacious compared to the little rooms on the ITU so my mind wasn't so focused on the paranoia.

Again, this helped with the dependency of getting out of the supportive environment I had been locked up in as my mind wasn't so focused on the symptoms. I tried to give myself some positive reinforcement about this when coping without the intensive nursing. Now the crisis episodes were not going to be so

bad and maybe I could get through them a bit easier. This especially as the being more occupied with the more distracting environment of the usual ward there might be some more strength for this.

The other factor with being let out was I could walk around the woodland in the hospital grounds and visit the local town centre and its river walk with relaxing water. This added to the sense of freedom I had forgotten about when locked up. I was able to clear my head more by being in calming places near nature and by being in wide open spaces with horizons, hill tops and scenery. Again, this helped with mood.

The best thing about it was the sunshine since when on the lock ward there any of this was hardly. So once out and about again it helped me appreciate the natural surroundings and enjoy the freedom more. This required a lot of getting used to again as and took a few days for my senses to get used to this. I found I could combine sun with other therapeutic experiences like sitting in a riverside café enjoying a cup of coffee.

On the intensive therapy ward there was nothing to break the day up as by getting off the ward for a while and nothing else was put in place to prevent the monotony of being in there. The highlight of the day was the prepared food which at the time was of very poor quality so even this peak was not effective. Fortunately, since then the food provided in hospitals has greatly improved so this problem has been solved.

The pleasurable aspects of being set free were tremendously important for coping with low mood in there as I found being responsible for 9/11 quite upsetting. When during a constant state of anxiety this thought of being released did occur to me when there was nothing else to distract me from it as with the usual hospital conditions. The answer I knew was to hang in there and get through the confinement when things would be more therapeutic for me afterwards.

Fortunately, the depression was held in check in a lot of ways, so I never got the full force of it. It was instrumental in dealing with it that I had family support. Their love and knowing they cared about me was a resource to staying happy. Then when I was back on the usual ward, I was allowed four hours leave during which time I could go home and see the kids and other relatives in my family which cheered me up a lot after the confinement.

So, I was also lucky in a different way in that I never experienced low mood in combination with being frightened and the two together would have been more traumatic. Maslow in his pyramid of self-actualisation stated that safety needs must be met before emotional ones come into play and when frightened and terrified this prevented feeling low mood at the same times. This however is not true for everyone and could be a potential problem in some cases.

The other problem was that sat on my backside for three weeks meant I wasn't getting any exercise. So, the therapeutic effects this can have on the depression of being locked away for so long were not available. This combined with the fresh air and sun again made me feel physically healthier and provided a focus through being active when out which also helped calm my nerves.

The other thing about being let outside was that the exercise got me breathing properly again which was more difficult when being locked in a room. In there, my mind was so focused on the paranoia I wasn't often even remembering to use relaxation techniques. Also, the breathing was difficult as there was no room to breathe in the small space, I was confined in. Going for a walk for example is more relaxing than trying to take deep breaths in such conditions.

So once out the exercise was making me breathe and was calming me down enough to appreciate the surrounding more. I began to feel more like my old self and was able to appreciate the lovely historical surrounding of our local town centre. These ways of calming down were all necessary to enjoying things again and the feeling of being calm was of much value in addition to this.

The other relaxation technique that is always recommended was safe place imagery. Yet when locked up I associated the place I was in with increased feelings of paranoia. The image work was very difficult. So, I found being in there was reminding me of causing 9/11 instead of cancelling out counterposing these thoughts to feeling somewhere protected. On release from my captivity, I was able to go home and so was living in a safe place and this aided getting better and recovering from the incarceration.

The other point of contrast from the usual ward as compared to the intensive unit was that being allowed out again made coming back to the ward much more pleasurable. Although a lot of people find this very confining this was never my experience, and I didn't mind being in there. This was because given that there were lots of good things to do it still made life enjoyable until I was going to be discharged.

Gradually things returned to normal when let out. then I started to employ the coping strategies that got me discharged from the usual ward and I was able to go home. All the same my time on the intensive ward stuck in my memory and I didn't forget how it had made things worse for a while at various different points. Although it had helped in many ways it had created an intense fear of the symptoms getting so bad again that I might have to be back in there.

Conclusion

Being on the ward made things more stressful at first and the symptoms began to deteriorate, even on what I was experiencing which had first got me admitted to the intensive unit. This was all the more reason to be there and with proper social contact one to one I gradually came round with the help of the nurses in there. The problem was over time that being on the ward was becoming stressful in itself and there were few ways to find an outlet to the pressure as compared to being on the usual wards to be found in psychiatric hospitals.

It is necessary to be aware of the problems this form of confinement can create for an illness like schizophrenia and it is necessary to keep the length of the admission to such a ward as short as possible. Even with the possibility of worsening symptoms in there the extra help will mean you can eventually be discharged which can subsequently help with the process of recovery, though it also means overcoming the feelings of dependency this intensive unit can create. Overall, the compact design for the

unit can help in the way it is meant too but this can cause severe problems we must be aware of when the ward is being utilised.