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National Paranoia Network, Limbrick Center, Limbrick  
Road, Sheffield, S6 2PE. Phone: 0114 271 8210. Mob:  
07590837694 Email: peterbullimore@yahoo.co.uk

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## ***Updates on the Network and People Involved***



Kate started hearing voices aged four. She would see visions of a man and woman in period clothing and also a little girl but they never spoke. After her mum died she was placed in children's homes. In later years she became homeless, she then met a man who she fell pregnant to. Kate now has four children. Through abusive relationships and constant pressure from social services, she felt she couldn't take anymore and made a suicide attempt. She was admitted to a psychiatric hospital and given a diagnosis of post traumatic paranoid schizophrenia. Things that help her now are working for the paranoia network, sharing her experiences with other voice hearers and people who experience paranoia. Getting involved in a hearing voices and paranoia support group changed her life.



Tori spent many years suffering from severe and debilitating depression. Eventually, after learning how to deal with it, Tori decided she wanted to help others who suffered from mental distress and trained to become a clinical hypnotherapist then later a counsellor. She has experience of working internationally with a wide variety of problems. She also teaches people how to work with depression.



Peter is a voice hearer who spent ten years as a psychiatric patient enduring many bouts of severe paranoia. Through learning holistic approaches and with support of the Hearing Voices Network he was able to reclaim his life from the system. He facilitates a hearing voices and paranoia support group in Sheffield. He also runs his own training and consultancy agency, Asylum Associates, and is the founder member of the Paranoia Network. He delivers teaching on hearing voices and paranoia internationally. He also teaches on the COPE initiative at Manchester University and currently undertakes a research post at the university looking at a collaborative working between voluntary sector organisations and the university, he is also undertaking research into what recovery means from a service user's perspective. He co-authored the workbook Asking the Questions with Paul Hammersley and Professor John Read, a guidebook around childhood trauma.

## **Dealing with Inactivity and Shutdown in Psychosis**

Written By: Hilary Mairs



Psychosis affects different people in different ways. Some people may hear voices or develop beliefs or ideas which are unusual or distressing. These experiences have been called 'positive symptoms' by researchers because these voices and beliefs were thought to be extra to normal experiences, although we now know that hearing voices and having unusual ideas is common in the general population.

Other people find that they lose interest in what is happening around them, stop doing things they used to find pleasurable/ are expected to do and no longer enjoy day to day activities. This inactivity may be accompanied by a form of 'shut down' where people experience few thoughts and feelings or find it hard to share what are described as 'negative symptoms' by researchers and mental health professionals. People with these problems report a lack of motivation and energy and sometimes a frustration that they are less active than they used to be. Whether it is helpful to think of these experiences as negative symptoms is questionable. Negative symptoms are recognized as an identifiable part of mental illness by health care professionals and knowing this can relieve some of the self blame and hopelessness that some people feel with these experiences. The idea that they are a medical illness does, however, pose some problems. For example knowing that these experiences are

negative symptoms suggests that there is one psychological cause and that the most useful treatment will be a medical one.

Some studies have tried to find biological causes, such as changes in the structure of the brain, but there is still no overwhelming evidence to support this suggestion. What seems more likely is that there are a number of reasons why people become inactive, whether in thoughts, feelings, or activities. For some people 'shutting down' may be a way of coping after a stressful time, a bit like having time out after a physical health problem. For others, avoiding stressful situations may be a way of reducing other distressing experiences, such as negative voices. We know that people with mental health problems are often treated differently by other members of the general population and avoiding contact with other people may be a way of reducing exposure to stigma.

It is probably best to say we don't understand this set of experiences very well at the moment and don't really know how best to help individuals who are experiencing them. This is largely because researchers have been more interested in positive symptoms, although there is renewed interest in negative symptoms and a number of studies are underway to help us understand them better.

There are a number of studies that have claimed that medication can help to reduce negative symptoms, but these are often conducted by the drug companies that make them. Independent reviews of these studies suggest that they are not as effective as the drug company's claim. In fact, some

researchers have noticed that these drugs can induce a state that resembles what happens when people have negative symptoms. A recent study in the United States found that giving people without mental health problems a single dose of some of the drugs often prescribed for psychosis causes them to experience negative symptoms. So, it seems that medication is unlikely to be helpful and may even make these experiences worse.

There are also some studies that have looked at whether talking therapies can help with inactivity and shut down. Although the evidence for talking treatments is only limited, there is a suggestion that understanding what may have caused negative symptoms for each person is important. For example, if someone is recuperating after a stressful time which may have involved admission to hospital; it may be important to spend some time resting. If avoiding social events is a way of coping with voices, it may be helpful to find a therapist who can provide help with upsetting voices before attempting to return to socializing. But, for some people it may be difficult to find a reason why they are lacking in motivation and energy.

What may be helpful in this situation is to work with a therapist or friend to try to increase activity levels in a gradual and paced way. These strategies are usually called activity scheduling or behavioural activation in the psychological literature and were designed initially to help people who were depressed. They generally involved working through a series of stages. The first stage is to find out what a person's weekly routine looks like.

Sometimes people are surprised, when they record what they are doing on a day by day basis, by how much they are actually doing. The second stage is to think about which activities they would like to do more of and also what activities they are not doing but would like to include in their weekly routine. It is important that they include a mixture of things that are enjoyable, such as meeting friends and those things that are essential, paying bills, going food shopping and so on.

In the third stage, these activities are put in a list with those thought to be most easily incorporated into a weekly routine at the bottom, with the more difficult activities at the top of the list. The final stage involves trying to introduce these activities in a graded way. What is important, is that people work through this process at their own pace and steadily increase participation in activities rather than attempting to do too much too quickly. We are currently undertaking a study at the University of Manchester to see whether this way of working with people who have become inactive/shutdown is helpful and acceptable.

It may also be helpful to talk to family and friends and share some information about inactivity and shut down. One study has found that providing information for family members can help reduce levels of these experiences. The key messages that would seem to be useful are that inactivity and shut are common in psychosis and other mental health problems and understandably can cause some distress. Being supported to increase activities and daily tasks can be helpful as well as allowing people to opt out for a while if becoming active comes too stressful.





## **Hospital Hell**

*One man talks of his hospital trauma during his time in an old asylum.*

I'll always remember the day I was sent to an asylum. It was dark and dreary and the cold wind was stinging my face. Although I was reluctant about going I thought it would help me get better. I had no idea how traumatic it was actually going to be.

A few months previous I had been involved in a hit and run accident, resulting in me having to have my right leg amputated at the knee. I found this exceptionally hard to deal with, I mean I was a young lad, I wanted to play football and do the things other lads my age could do but my Mum and girlfriend ran around doing everything they could to help me. Unfortunately a few weeks later gangrene set in on my wound. I can still smell it whenever I think about it, ghastly it was. I tried over and over again to inform the doctor that the nurses weren't changing the dressings often enough but it fell on deaf ears and I had to have my leg amputated for a second time, This time all the way to the top of the thigh. This hit me hard and I started to forget who people were. It was this that got me admitted.

I was placed on a men only ward surrounded by people suffering with severe mental illness'. A lot worse than what I was

dealing with. For the first few weeks I was put in a room on my own but this was in a total isolation for 24 hours a day with no lighting. I had no visitors and wasn't even allowed contact with the other patients. Every morning at 6:30am without fail the nurses would come charging into your room and literally drag you out of bed, not once in all the time I was there were we allowed to sleep in later than that. Even though for the majority of the day we were sat around with nothing to do. I couldn't join in any games as I was never given any crutches or form of walking aid whilst I was there. Of course I was always promised one but it never arrived. I had to make do with shuffling on my bum to get around. This didn't help my health as found it degrading and extremely frustrating.

The nurses were never sympathetic and often were very aggressive to the patients on the ward. I once witnessed four nurses verbally abuse and beat up another patient for no reason what so ever. It was just their way of getting their 'kicks'.

The most extreme time I saw them harming a patient was when a male nurse started hitting an 83 year old man who died as a result of this. Quite a few of us complained about the incident but nothing was ever done about it. There was a male hairdresser working at the hospital who advised everyone that it was in their best interests to keep quiet about what they saw, otherwise life would be made even harder for them.

*"They used to say we were mad."*

The staff didn't care about us. To them we were just 'mad', which is something they used to call us on a regular basis. They



used to call us all kinds of names and tell us we weren't right in the head. At one point I actually started to believe them. One of their favourite forms of torture was the hot and cold baths they used to give us. Depending on what mood the nurses were in you would either get a bath full of freezing water or a bath full of boiling water. You could hear the screams from the patients echo all around the hospital as they were forced to sit in these baths. There was never any soap or anything for a proper wash but I suppose that was probably a good thing!

One of the worst times in there was when I was moved out of my 'cell' onto the communal ward. I woke up in the middle of the night to find I was being strangled by the man in the bed opposite. I couldn't breathe and I was struggling to be able to shout for the attention of the nurses. I had just started to slip into unconsciousness when they arrived and pulled the man off me. Luckily I was just left with a few bruises but it could have been a lot worse. For the majority of the nights I spend on this ward I also woke up to find someone had urinated in my shoes. I never found out who it was but I often used to wonder if they were watching me until I fell asleep. This made it even harder for me to go to sleep as I already found it hard after the strangling incident. Most nights I was too scared to close my eyes.

During my time I never once received a single letter sent to me from my Mum or girlfriend, although when they would come to visit me they would insist they had sent them along with some money so I could buy some cigarettes. I told them I'd never received them but whenever they would question the nurses about it they would simply say that I was crazy and that I *had*

received the cigarettes and had shared them all out with the other patients, apparently I just couldn't remember. This used to really anger me as I knew it must be the staff stealing the money. It also upset me that my family no longer believed what I said.

I couldn't wait for the day I turned 21. I signed myself out that very day; there was no way I could take anymore! My Mum tried to persuade me to stay until I was well again but once I was back at home I was better than I had been in ages. I received a pair of crutches within a couple of weeks of leaving the hospital and was back on my feet in no time. 18 months later on, I received a prosthetic leg and my life went back to normal.

I'll never forget my time in the asylum it can only be described as mental torture. There is no way anyone could ever get me to go near that place again, even after all these years. I feel sorry for the people who spent their whole lives in there because I know *I* wouldn't have been able to cope.

**The National Paranoia Network are pleased to announce that Professor Alec Jenner has agreed to be their patron.**

**Alec Jenner was head of department of psychiatry at Sheffield University. He was also co-founder of Asylum magazine for democratic psychiatry. Alec was radical in his day, forming working relationships with R.D.Laing, Loren Mosher and Thomas Szasz.**

## **A short history of Asylum 1986 - 2011**

### **The early years: 1986 - 2002**

In the spring of 1986 Asylum costing 50p but "Free to Inmates" was launched. The first cover announced the highlights of the initial edition as follows: -

### **Exclusive interview with R. D. Laing: 'Psychiatric Democracy in Italy, The Politics of Mental Health'**

That captures most of the intentions of the founders. We were a group of sufferers and professionals much influenced by the "antipsychiatry" movement of the long past sixties and galvanised into action by two visits to England of Mental Health Workers from Italy who came as missionaries for Psichiatria Democratica in Italy. The University Department of Psychiatry in Sheffield had made a slight profit out of the visit and that enabled us to start publishing. Lin Bigwood and Phil Virden had similar ideas about a magazine as we did in Sheffield. . For several

years Phil did much of the work almost in the way in which Terry McLaughlin later did. Neither has been significantly rewarded. Over the years and despite several crises we have gradually become more sophisticated, and realistic money-wisely, but never secure.

Our aim was and is to struggle towards achieving what we thought was the best of the system in Trieste in the late eighties. There the great ASYLUM San Giovanni was now a complex of apartments for ex patients, of art studios for everyone, space for theatres and cinema performances and a perpetual discussion of what more could be done to humanise mental health services. There were co-operatives and a restaurant in town as well as well as small friendly units with a few beds for short stay during crises as well as facilities to sit together to eat and to chat and to see the mental health workers. We liked the realisation that the total ambience of everyone's' life is of central importance to their mentality. They had realised that much that is therapeutic comes from the arts, from sharing good things, from eating, drinking and laughing together. Our central aim in encouraging those who felt hurt by the system to write was the hope that it would help, them to express their views, which would also be discussed. So we tried to offer them "a proper place at the table". There they would be given as good a chance as is possible to be taken seriously. That was also very much to set mental health and those thought to lack it in their true political and economic setting. Sometimes when angry one can write what one might be frightened to say and we

accepted the need at times to do so anonymously. We have also an urge and a tradition to accept articles by allowing space for what is sent to us. Reality limits complete freedom!

We have remained independent of financial support from anyone other than subscribers and workers and we have no overwhelming allegiances except to the right to express one's own opinion, and for others to have the right to challenge it, and certainly a duty to listen.

Many people have worked voluntarily for us Peter Good did with our first cooperative printer in Huddersfield. Then we moved to Montenev Press in Sheffield a part of a workshop set up by among others David Blunkett. There unemployed workers printed ASYLUM for the cost of the paper and ink, but we did make good will donations to them. Then a group from Manchester, especially Nigel Rose, Paul Baker, Mark Greenwood and Ann Walton played central roles. Throughout Mark Hinchliffe has been our poetry editor, and for most of our existence aided at different periods by Jane Paffey and Paula Quick. Helen Spandler has also helped us over several years, as has Philip Hutchinson. Stephen Ticktin has been our London agent, and very involved since the early days, so too was Tim Kendall. We are indebted to all these people and to so many others - some of whom are mentioned in our current list of the collective's members.

We chose the title ASYLUM for its original etymological meanings through Latin from Greek to English. That is of a refuge, and also of there being a right not to be seized. We were influenced too by knowing that ASYLUM was the original title of what became the British Journal of Psychiatry!

After a quarter of a century, of inevitable inefficiencies, disasters and chaos, we are proudly struggling on. It should not be surprising that an amateur outfit of volunteers, many with their own problems should have had several severe hiccoughs, for which many have kindly forgiven us. We do hope much of that may now be behind us. We still hope to be able to continue to make a significant contribution to understanding and ameliorating mental suffering of so many people. We do certainly want to be among those giving them a voice, and an attentive audience, and when and where possible a sympathetic response.

Alec Jenner. Founding Editor of Asylum

## **2000 - 2007: In The Service of a Revolution in Mental Health**

By the end of the millennium the Collective was showing signs of weariness. Rumours were afoot that the magazine had folded (which were not true) and others suggested that the ideals and principles which had driven the Collective should be consigned to history. The rampage of market forces and the specter of global policies of



coercion was a depressing picture. Activist networks were either falling into the clutches of the drug companies, becoming reliant on government funding or commercial operations serving the interests of the professional classes. Asylum could never do that.

Yet the last decade in particular had seen the rise of a new generation of survivor workers and activists. Paradigm shifting research in the Netherlands by Marius Romme and Sandra Escher had led to the blossoming of the Hearing Voices Network (HVN) and an international hearing voices movement. (Asylum collectivists were in the forefront of this development.) Psychology Politics Resistance (PPR) was founded in 1994 uniting critical psychologists with non psychologists against the abuses of psychology. The newsletter of PPR was formally incorporated into Asylum magazine in 2001. Progressive psychiatrists founded the Critical Psychiatry Network. (The foundations of this can be traced to an open letter from Romme published in Asylum).

Above all a radicalised survivor movement had brought new hope of ending the barbarism which has characterised psychiatric practices. Mad Pride internationally has recaptured the spirit of artistry and rebellion which was alive in the sixties and served well the democratising project in Trieste, Italy. The No Force grouping has revealed a new potential for activism. This summer the establishment organisations which in the form of the Mental Health Alliance were in opposition to the

reactionary Mental Health Bill, managed to call off a mass demonstration in London. No Force pulled off an impressive demonstration at the last minute. The ideals of the No Force project have been taken up by activists throughout Europe, determined to check the forces of reaction at the heart of the European Union.

Asylum has not only been proud to report on these events but has taken this inspiration as new energy to develop the magazine. In later years the magazine was sustained by the hard work and finance created by Peter Bullimore, Wayne Clay, Peter Cawley and other members of Asylum Associates.

We will never have recourse to drug companies or sell out the principles of the radical democratic movement within and against psychiatry. Please support this movement by subscribing to Asylum.

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# **The Australian Paranoia Network.**

By Chris Rickman.

After attending Peter Bullimore's working through paranoia seminar in Perth at the Department of Health I was astonished and inspired as to the depth of knowledge, experience and courage this man has on the often taboo subject that is paranoia. After receiving in-depth information from Mr. Bullimore on paranoia I worked to establish the Australian Paranoia Network, a network closely modelled on the England's Paranoia Network and its core principles and beliefs.

To date, several successful self help groups have occurred in the Perth metropolitan area and I believe the success of these groups was the result of being able to talk about paranoia in an environment and manner that, until now, did not exist for paranoia sufferers in Australia. Many of the group participants had only ever been involved in direct consultation with a doctor to address their paranoia and this time was often brief and had time constraints. The self help groups allowed people to discuss at leisure their beliefs without fear of judgment and allowed group participants to confide with others. Other group participants have begun to educate themselves on paranoia and gained insight into their own experience with the aid of others in the group giving them a sense of control and empowerment over paranoia beyond the scope of taking medication or self medicating. The

Australian Paranoia Network is currently establishing a website.

Below are some testimonials of two of the groups participants.

'I had been self medicating with alcohol to hide what I thought was personal weakness. Only through mature, intellectual discussion at the group have I been able to identify that I am not weak and I feel stronger already for addressing the paranoia that has wreaked havoc on my life since I was 18 years of age.'

Mark, 25

'I was able to open up and discuss with people who I regard as my mates, elements of my experience with paranoia that I have never told a doctor before. To be able to talk about this in a calm and peaceful environment about something that has dictated my very life is something I am very thankful for. To be able to confide like this regularly with people I know and trust is absolutely priceless'

Aaron, 26

## **My Personal Journey**

My experience of paranoia began in earnest in the closing days of 1996. On New Year's Day 1997, I was taken to hospital after trying to take my own life. Up until then, I had experienced what I would describe as a 'normal' level of paranoia, very occasionally thinking that people who knew me might be talking about me or thinking that girls were laughing at me - the experience, perhaps, of a lot of insecure young men.

I was already in contact with psychiatric services for acute depression, and was already disillusioned with psychiatry. My experiences in the local psychiatric hospital in 1997 did nothing to dispel my pessimistic views.

The events that lead to my breakdown are complex and unpleasant, but very real. I know a lot of people experience worse things than I did and are not believed. The nastiness of the people who subjected me to very intense psychological abuse seemed to be beyond the comprehension of the doctors and nurses I talked to about it. Had I received the appropriate interventions at the time, the impact of my unpleasant experiences would probably have been lessened greatly. Effectively, I received only one treatment – 90 milligram's of stelazine 3 times a day. Despite devastating side effects and my

frequent requests to come off the medication, this continued for several months. I was discharged from the hospital and stayed at my Dads house. By now, the paranoia had really kicked in and I was too scared to leave the house. The people who had bullied/abused me had threatened me a lot, and I thought I might be killed. I also felt my Dad might be in danger, and I asked him not to leave the house either. My Dad seemed to think the doctors had the right idea, and dismissed everything I said as pure delusion.

This period was probably the darkest of my life. I felt deeply resentful and angry towards almost everyone. No one seemed to believe me about what had happened and I felt utterly alone with terrible feelings of fear and anxiety. I strongly feel that the Stelazine contributed to my anxiety. I was unable to function on this drug; I even had trouble walking down the street when I was eventually able to leave the house. I seem to be prone to the worst of the side effects of neuroleptics.

The psychiatrist I saw in hospital in 1997 was sacked. I still don't know why. I was given a new psychiatrist who put me on a more modern medication. The side effects of this drug were still bad but much more bearable than the stelazine. They say that the more neuroleptics you try, the more likely it is that you'll find one that works. This



process of trying out various medications can take many months, and for me went on for years. During this time, despite the debilitating side effects, I found ways to deal with my symptoms and ways of coping with a new way of thinking. Perhaps, instead of finding a drug that works (which for me has never happened), people simply begin the process of recovery over these months or years of being given different drugs. The human organism, like all organisms, has the tendency to maintain a kind of balance or homeostasis. Over time, psychiatric patients seem to learn ways of coping with their symptoms, and I should imagine this process would occur, perhaps with varying degrees of success, with or without medication.

Months passed. I tried calling for friends, but they all treated me in a way they never had before. Word had got round that I had gone mad. Now they merely tolerated me, and answered my phone calls with a sigh of weariness. It didn't help.

I moved into a supported living environment. I was now on another medication, I think it was Olanzapine. I also had a new psychiatrist, who I only saw once. He said I did not suffer from any mental illness and that I could come off the medication. Ironically, I was at this point becoming truly psychotic. I thought I was being followed everywhere and that everyone in the town where I lived knew who I

was and what was happening to me. If I went into a shop and bought something, I thought the shop keepers conversation was a secret, coded message. I would spend a lot of time walking on the sea front. I thought certain radio stations were broadcasting secret messages to me and that my radio had a transmitting device in it so other people would know what I was listening to. I thought the people in the house opposite were watching me, so I put signs in my window with messages for them.

Following my new psychiatrists advice, I stopped taking my medication. Psychiatrists had always told me it was dangerous to stop taking the medication, but they never said why. The reason is that suddenly stopping neuroleptics leads to a reaction called the rebound effect. This occurs with other medications, not just neuroleptics – once the medication is suddenly stopped, the illness returns in a stronger form than which it was originally present. If I was only slightly mad before, the sudden withdrawal made me very much crazier. My 6 month tenancy in the shared house was coming to an end, and I decided not to renew it. The place was beginning to feel like a penal institution. The food was awful and the other tenants were getting on my nerves. I went to the local council and told them I needed somewhere to live, and anything would do. I took a flat in a tower block in a

rough part of Birkenhead. I had no furniture save a mattress, no gas or electricity for a few weeks. Eventually I got a table and chair and a cooker and got the gas connected. I spent all day walking around Birkenhead, following signs I perceived in the environment. A certain advertising hoarding told me to turn left. A piece of rope in the road meant carry straight on. If I saw a person scratching his nose, I was meant to follow him. Car registration numbers were secret messages. A person talking to me as I bunked the train talked in riddles I was unable to solve. The person in the tower block opposite was watching me. I had to slither around on the floor so he couldn't see me. All of this was accompanied by a huge amount of warped reasoning and problem solving.

I wore the same black pants, black top and German parker for weeks on end. I knew I stank, but I felt great. I had never felt so happy and content. Life suddenly seemed magical and amazing. I was living like a bum but I felt like the king of the world.

I only lived in the tower block for about 2 months. One night I was lying on my mattress in the dark feeling great when I began to hallucinate. At first I was amused, then it began to get scary. I chose to sleep in the kitchen with the light on. The next day I went to my Dads as I didn't want to sleep at the flat any more. I hallucinated more

that night at my Dads house. I ended up in hospital and the hallucinations continued. I spent the Xmas of 1999 in hospital, back on meds and miserable.

After the hallucinations, I spent 3 years living at my dad's house, depressed and drinking too much. Things were quiet. I was on Respiridone by now. Occasionally, in a rebellious mood, I would stop taking the medication for a few days. This always sent me into a dark, trance like state. In this state, I would dream of revenge and how different it could have been. I told my cpn about this. He was a great guy, and explained that the trance like state was due to withdrawal from the medication – the rebound effect. It was around this time that I found out I had a diagnosis of schizophrenia. A mental health worker made a phone call on my behalf and mentioned that this was my diagnosis. I don't know when or by whom the diagnosis was made. No one told me or my Dad about it.

After 3 years at my dads, I moved into another shared house with another supported living housing association. I had a few new friends and my social life picked up a bit. I lived in the house for 6 months then moved into a flat of my own. I was still quite depressed and not doing much with my life at all.

Around this time, I started jogging. I'm not a great runner but with the encouragement of a good friend I entered a few 10ks. Looking back, I think this was the start of my recovery. It was a slight increase in activity but it made quite a big difference after a while. I don't always enjoy running, but, as my running friend Chris would say, it's money in the bank. This invisible money buys you a good feeling. Real money doesn't buy you that. It doesn't for me anyway.

After this, there were still episodes of crisis but no hospital admissions. I think I've been there 5 or 6 times by now, but I don't think I'll be going back. There have been no more overdoses or self harm, no more hallucinations. Even a die hard medicalist would have to admit that an anti psychotic couldn't suddenly start working after 3 years of not working at all. Running kick started the inherent ability to get better.

The next big step in my recovery was starting a new medication – an antidepressant. They say that schizophrenics sometimes suffer from depression, whereas I see myself as a depressed person who experienced quite a bit of psychosis. Indeed, one psychiatrist said I was probably psychotically depressed. I think that psychosis is the illness and it takes many forms, from mania to delusion to hallucination. Why else would bipolar patients

sometimes be prescribed anti psychotics? When I had trouble sleeping, why did my CPN suggest lithium? The divisions between different diagnoses are clearly defined in the textbooks, but much less so in real life. I often wonder why psychiatrists don't notice these glaring discrepancies in the theories they try to put into practice.

My experience of paranoia suggests that it is an unusual way of dealing with stress. Paranoia also provides answers to many otherwise unanswered questions. It provides simple rules for living. And it fills the vacuum that trauma can produce. Nature abhors a vacuum and the human mind hates the uncertainty that trauma or stress creates. Part of my recovery has been to simply observe paranoia, but not to buy into it. When I get paranoid thoughts, I think to myself 'here's those thoughts again- wonder what they'll say this time?' It's part rationalization, part mindfulness part not giving a shit so much. Eating regularly and healthily and regular sleep are the foundations of health. Avoid friends who don't understand or care. Read about what you're experiencing-you'll discover no one understands what's happening to you as well as you do. Most of all, you must be absolutely determined to improve your lot. Nothing takes the place of persistence. A healthy dose of anger is good. It doesn't



hurt to keep your sense of humour. Never, ever give up. And if you do give up, just start again.

I don't think I'll ever be free of paranoia. But my paranoia is evolving, and sometimes it tells me good things. Instead of inferring threats from people's conversation, sometimes I hear compliments. I trust people a bit more. Paranoia affects my life still – I know not to listen to certain radio stations, I avoid a lot of people I used to consider friends and I can't switch the lights on at night (it's complicated). Even though my diagnosis has evolved from schizophrenia via several junctions to chronic paranoid schizophrenia, I feel almost unaffected by this. My reading and life experiences suggest that there is really no such thing as schizophrenia, there is only experience and reaction to experience. I know I've been mad at times, as have others I've known. But the medical textbooks don't explain, understand or even document my kind of experience. My psychiatrist doesn't have a clue. I seem to be the only person who even knows the cold facts of my experience, so it must be up to me to find the answer. I'm not saying people should stop seeing their psychiatrist. It's something we have to tolerate. But recovery seems to take place outside of psychiatry. Personally, I don't think psychiatrists want you to recover – if everyone started

getting better, they and their buddies at the pharmaceutical companies would be out of a job.

### Recovery checklist.

- 1) Regular sleep, healthy diet.
- 2) If it works for you, medication.
- 3) Exercise helps.
- 4) Meaningful activity, such as voluntary work.
- 5) Having at least some friends who don't have mental health problems.
- 6) Educating yourself about mental illness. Your recovery is your own responsibility but psychiatrists can be very protective of their specialist knowledge. Detailed information about psychiatry can be hard to find but it's worth persisting. Realizing how little is really known can be empowering.
- 7) Identify paranoid thoughts. Ask a friend or CPN if a certain thought seems rational. Don't be afraid to admit you are wrong in your perception.
- 8) Challenge yourself and be open to change. No one is absolutely right about everything. If you didn't realize that your thinking can be flawed, you probably wouldn't be reading this.
- 9) Try not to jump to conclusions. Be flexible. Sometimes a coincidence is just a coincidence.

10) Don't imagine that your life is over because you have a diagnosis. You are probably not a dangerous lunatic. People of that caliber tend to become politicians or something like that.

## Suggestions

When struggling with a paranoid thought, try to give it a percentage relating to its likelihood of being true. I found that when I started doing this, I was surprised at how low the average percentage was. It enabled me to worry a lot less.

When someone I know said something that made me paranoid, I struggled to try and reach a decision about how I should think about it. I realized there were 3 basic possibilities.

1. I was being irrational and there was no way my paranoia related to anything other than my own illness.
2. I was being totally rational and the person meant to hurt me in some way

3. It was a bit of both – the person was being a bit nasty but I was reacting in a way that wouldn't help me.

I have applied this reasoning quite a few times and always end up at the last point, point 3. There are a lot of nasty people out there who like to make you feel bad by communicating their dislike of you in a subtle way. They think they're clever. I try to avoid such people.

I found a course on mindfulness run by the local psychology service to be very helpful. Mindfulness is a different way of looking at thoughts and emotions. It suggests that instead of being swept away by negative or painful thoughts, you simply learn to observe the thought or emotion or sensation, sit with it and endure. This approach states that pain is an unavoidable consequence of being human. Suffering, however, is optional. I know that sounds crazy or unreasonable, but with quite a lot of practice and dedication it can become a fact. If you can't get on a mindfulness course, there are lots of books and CDs available on the subject. Try googling Jon Kabat Zinn. Russ Harris also produces some good CDs with mindfulness exercises on them.

No one told me I could recover. My friends abandoned me and my family still don't take me seriously. I thought my life had been ruined. For a while, it was a ruin. It's been

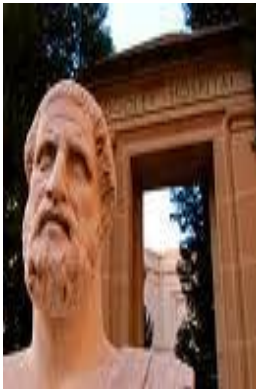
like surviving a 13 year long car crash. I have scars, both physical and psychological, but I'm still here. I found it difficult to be open to anything new and I found it even more difficult to maintain a positive state of mind. Practice makes perfect. Just walking down the street can sometimes still be challenging but I'm sure a lot of people feel like that. Happiness, like love, is a gamble but ultimately worth it. I've learnt to be open to change, because the process of change is the only thing that stays the same.

John McHugh

# **Starting and Sustaining Paranoia and Hearing Voices Self-Help Groups**

## **A Facilitator's Guide**

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Hippocrates



Dr Sandra Escher



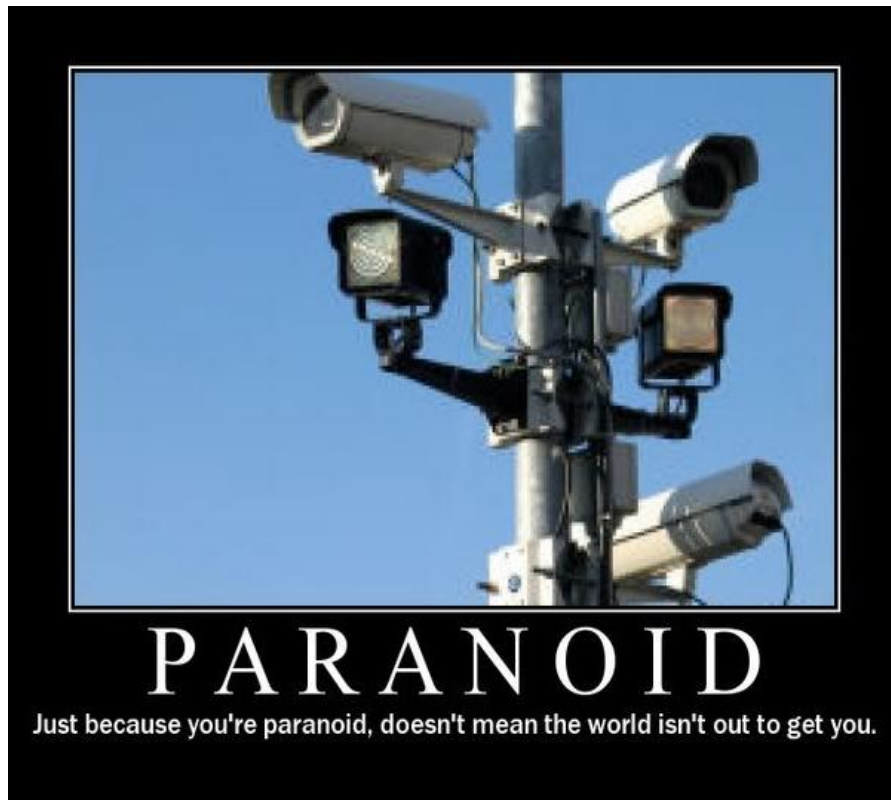
Professor Marius Romme

**Written and compiled by Peter  
Bullimore, Kate Crawford and Tori  
Reeve**



Understanding Paranoia

Cost £2.00 inc Postage



**Peter Bullimore**

**&**

**Tori Reeve**

# National Paranoia Network

## In House Training

National Paranoia Network offers in house training around understanding and working through paranoia, starting and supporting paranoia support groups and asking the questions around childhood trauma.

All our prices are competitive and negotiable. Each training day can be tailored to suit your organisations needs. For more details email:

[peterbullimore@yahoo.co.uk](mailto:peterbullimore@yahoo.co.uk) or call: 0114 2718210



## **RATHBONE REHABILITATION CENTRE**

### **How to cope with hearing voices**

Hearing voices expert Kate Crawford helped relaunch the Rathbone Hearing Voices Group aimed at providing a range of non-medical ways of helping people who hear voices. Kate, who facilitates the Rathbone group formed three years ago, is an ex-service user who herself hears voices. She is part of the Hearing Voices Network, an organisation that offers support, information and understanding to people who hear voices. She facilitates a number of self-help groups in inpatient units across the North West as well as speaking at international conferences. Clinical psychologist Dr Alison Booth said: "The Rathbone group offers a forum for service users to discuss difficult thoughts and feelings and experiences of voices, and receive support from others who have had similar experiences. "Kate offers advice about coping

strategies, ways to accept and live with voices, and information about her own experiences where appropriate. The group has a non-medical focus and is an opportunity for patients to talk freely about their experiences."The group runs weekly meetings and we now hope to promote the benefits of the group for all patients as well as those who hear voices. The launch was also attended by an ex-service user who facilitates a community hearing voices group to enable us to build links with groups that patients can attend after leaving the unit."Kate, who describes herself as 'an expert by experience', said: "The Hearing Voices Network aims to de-stigmatise voice hearing experiences, leading to greater tolerance and understanding of this phenomenon. This can be achieved by promoting more positive explanations and voice hearing experiences and giving people a framework for developing their own ways of coping."I always tell people it's important to remember that the voices can't make you do anything that you don't want to do; you don't have to obey them."

More information from Hearing Voices Network

Tel 0114 271 8210 or [www.hearing-voices.org](http://www.hearing-voices.org)



Kate Crawford front row second left



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