A patient's journey: living with paranoid schizophrenia

Stuart Baker-Brown

Stuart Baker-Brown developed paranoid schizophrenia in 1991 and received a diagnosis in 1996. This is his story.

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BMJ 2006;333:636–8

Moscow 1991

Paranoid schizophrenia took its strongest grip on me after I had visited the former Soviet Union in August 1991. During my visit I took part in the marching on the streets of Moscow against communism and against the communist hardliners who attempted a coup against Mikhail Gorbachev. During my stay I began to feel very stressed because of the political unrest and uncertainty. I marched with the people not because of any political beliefs but because of the vast importance and history of the occasion.

I can clearly remember the moment paranoia took its grip on me for the first time. One night after I had marched on the streets I was woken by a telephone call in my hotel room. To my surprise, a man on the other end was shouting and swearing at me in Russian. I immediately put the phone down. I was extremely worried, and my heart began to pound heavily. Within a few minutes I found myself feeling very anxious about being in Moscow alone and began to regret my involvement in the marching.

A difficult homecoming

On my return to London I felt sick with worry. I was panicking about the situation I had just returned from and became concerned about possible persecution by the KGB, being a foreigner involving myself in their country's business.

As I look back now, I feared the KGB not from any personal experience but from reputation and the negativity planted in my mind by "home beliefs" about the Soviet Union. The worry of the phone call in Moscow and fear of the KGB began to take a hold on my life. As I write these words, I can recall my paranoia and fear building up on a daily basis.

I tried to convince myself that I was under no threat and that my fears were unjustified, but I quickly began to be afraid of everyone and feared that my life was in danger. I did not know what to do. I had no idea that I could have paranoid schizophrenia; I did not even know what schizophrenia was.

Stress and paranoia began to take their toll. I quickly became confused in my thinking and obsessed that I was being followed. Often, when I got back to my bedsit after work I would huddle in the corner of the room in fear.

As the weeks passed and pressure took its toll, I had to take time off work. Anxiety and paranoia were now quickly and devastatingly beginning to run my life, and a deep rooted illness was setting in.

During this time I had my first and worst psychotic experience. It was an extremely frightening time and still scares me now as I think of it. As I lay on my bed trying to relax, I suddenly found myself in complete darkness. I had the experience of being physically vortexed into my own dark mind. I cannot truly explain what went on, but the feeling of it still terrifies me. I screamed to be let out, and as I screamed I found myself back on my bed with a strange sensation around my head. It was as though I was sucked into my own dark mind away from any life or reality. It was this type of experience that finally gave me the courage to approach a doctor. I was immediately signed off from work and referred for assessment with a psychiatrist in London. I was now at the beginning of my full blown illness, and I decided to leave London and move to Devon, where I thought it would be harder for the KGB to find me.

I found a suitable flat on the edge of Exmoor. It was a perfect place to hide away and try to cope with my illness. In retrospect, I think I was also hiding my state of mind from the public and my friends, ashamed that I might have a mental illness. It took me many years to understand that it was, in fact, a strength to admit my illness and seek help and more of a weakness to hide away from it.

Meeting the enemy

In 1996, four years after leaving London and having moved away from Devon, I was finally diagnosed as having paranoid schizophrenia. I remember feeling relief, as though I had finally met with my enemy. Straight away, I researched paranoid schizophrenia and used information provided by the British mental health charity Rethink to start to learn about my illness. With information supplied by Rethink, I immediately related to symptoms such as voices, psychosis, false and irrational beliefs, thought disorder, suicidal thoughts, depression, lack of motivation, the feeling of being controlled by outside forces, and of course the paranoia and fear of persecution.

Before I received the diagnosis I had slipped into depression, which lasted for years. Because of

Resources

Rethink (www.rethink.org)—British charity dedicated to improving the lives of everyone affected by severe mental illness, whether they have a condition themselves, care for others who do, or are professionals or volunteers working in mental health

SANE (www.sane.org.uk)—British charity that raises awareness and respect for people with mental illness and their families; improves education and training and secures better services; does research into the causes of serious mental illness; and provides information and emotional support to people with mental health problems, their families, and carers

SANE Australia (www.sane.org)—Australian national charity that does a range of work similar to that done by SANE in the UK

National Mental Health Association (NMHA) (www.nmha.org)—The United States' oldest and largest non-profit mental health organisation, which covers all aspects of mental health and mental illness; works to improve the mental health of all Americans, especially those with mental disorders, through advocacy, education, research, and service

depression and the lack of proper support from my local mental health trust, suicide began to be a real option for me. I could see no future and found little cause to stay alive. What hindered my life just as greatly as my schizophrenia was the mental health trust's attitude towards me and my illness.

Once diagnosed, I was told that I was a "service user" rather than a "patient." My partner was not a partner but was labelled as my "carer." When she became my wife, she was still referred to as my carer. I was unprepared for the weeks after my diagnosis, during which my psychiatric nurse told me that it was very likely that "I would never work again in my life" and that the rest of my life would probably be about "fighting to keep my schizophrenia under control." I had never contemplated not working again and had always assumed that I would gain control over my illness and one day, sooner rather than later, be able to return to work.

These statements from my nurse threw me completely. More was to follow from the trust. My nurse told me that I had "to prove" that I could function as a normal member of society and that I would not be "a threat" to anyone. I was shocked by these words and this very poor attitude towards me and my illness. The demoralisation caused by my illness was complete, and soon after receiving my diagnosis I became a broken man. The trust's lack of proper care and understanding of my needs as a person with schizophrenia, and being treated more as a "condition" that needed controlling than a person who needed "understanding," made sure of that.

A bitter pill

Unfortunately, the mental health trust's attitude towards me helped me to feel persecuted and stigmatised. Because I was treated as a possible threat, I myself began to believe that I was a threat and so withdrew from life. I was also treated as though my diagnosis was all I was capable of being and nothing more. So, for many years, I went through life feeling that I was not capable of any achievement beyond coping with my illness. This attitude from the trust stayed with me until I finally broke free in 2004. Indeed, it still haunts me to this day and holds me back from participating in society.

I was treated with various drugs over the years, but I did not find one that truly suited me until 2002. Then, and after much arguing, I was finally put on the treatment I am still on today. With my general practitioner's support, I am able to manage my illness effectively.

Coping with my illness has been very hard—with the paranoia, fears of life, delusions, depression, anxiety, physical illness, and all that comes with paranoid schizophrenia. Previous drug treatment and a lack of motivation caused me to become obese. Before diagnosis I weighed around 14.5 stone (92 kg). In 2001, on my wedding day, I weighed 26 stone (165 kg). I have also been diagnosed as having type 2 diabetes.

A shoulder to lean on

My illness can be very powerful, both creative and devastating, and has left me broken and demoralised on many occasions. The illness and the inability to function in normal life—such as work, socialising, or being able to communicate fully—knocked all confidence out of me and left me feeling worthless.

The right to be "able" to work properly, to have a mortgage, to create a family, to learn, to live, and to function in society was taken from me by schizophrenia. The opportunities so-called "normal life" gives to other people are taken away from those who have mental illness. Severe mental illness can take everything away and can offer only devastation in return.

After a long hopeless battle, I was introduced to a Rethink befriender, Paul Brown, who slowly and carefully began to guide me to the life I now lead. It took time, trust, and a lot of care. Paul shone a brighter light on my illness, very different from that shed by the mental health trust. He offered me great support and a refreshing outlook, which helped to change my life. I had often remarked to people that I had felt more "policed" than cared for by my psychiatrist and psychiatric nurse, an attitude that helped to cause me to withdraw from life altogether.

Paul was a volunteer trained by Rethink to work closely with me. When I had known him for a little while, my confidence began to grow. He helped to introduce me back into society by taking me out for a coffee or even shopping at Tesco. He also helped me to understand my illness better. Paul understood that I was not a threat to society and that I did have a value in life. He understood that my illness was a part of me and not the whole. He was a shoulder I could lean on, someone I could trust. His support was vital and has contributed greatly to the good frame of mind I find myself in today.

One man's mountain

I have always been determined to overcome my schizophrenia and to show that great personal goals can still be achieved be someone who has lived with such a demoralising and destructive illness. In 2003, having won a Winston Churchill Memorial Trust travel fellowship, I trekked to the base camp on Mount Everest, Nepal. While photographing Mount Everest from Mount Kala Pattar (5500 m), I realised that I might wish to climb Everest in the future. I was drawn to do this; it seemed as though it would be my fate.

In 2005, I travelled to Tibet and stayed at Rongbuk for a short while. From there, you can see Everest in all its magnificence. I knew then that I wanted to climb the great mountain, to help to prove to myself, society, and healthcare professionals that I should not have been written off from life and that we can overcome the severest problems and scale the greatest heights.

I travelled to Nepal again in March 2006, trekking to Mera Peak, a recognised and well used training ground for Everest. Sherpas provided mountaineering training, which I enjoyed very much. If I can secure funding for my 2007 expedition to Everest itself, I shall be climbing with Dorjee Sherpa, who has climbed Everest 19 times, and a team of sherpas that includes my friend Nuru Jangbu Sherpa. I will ensure that I am able to continue with my treatment throughout the expedition.

Evaluation

I have always accepted my diagnosis of paranoid schizophrenia. What I refuse to accept is the label and the fears and misconceptions that are attached to it. I feel strongly that it has been the world of psychiatry, not society, that has discriminated and showed the least understanding of my illness. Paranoid schizophrenia is a greatly misunderstood illness, and misunderstanding from society and professional carers is harming many people who are already in much pain.

When I was given the diagnosis, my psychiatrist told my nurse that I was one of the severest cases of schizophrenia she had come across. With that statement, I should not be doing the things in life I am trying to achieve, such as attempting to climb Mount Everest next year. It is a shame that I feel I have to spell out that I am a good person who has never intentionally harmed anyone. Like other people with mental illness, I am intelligent, caring, loving, and creative, and I strive to be a good human being who yearns for a good, equal life, full of all the opportunities that any decent, respectful person deserves.

Too often these opportunities are taken from people with schizophrenia, because of our illness and because of the misunderstanding of our illness, our needs, and who we really are. I believe that the great misunderstanding of my illness and the discrimination and poor treatment I have received have been shameful and should not be accepted in the United Kingdom today. It has to change.

Competing interests: None declared.

To find out more about Stuart Baker-Brown and his Everest challenge, visit www.onemansmountain.com.

(Accepted 21 August 2006)

doi 10.1136/bmj.38968.608275.AE

Interactive case report

Fever of unknown origin

This case was described on 2 and 9 September (*BMJ* 2006;333:484, 541). Debate on the patient's management continues on bmj.com (http://bmj.bmjjournals.com/cgi/eletters/333/7566/484). On 30 September we will publish the case outcome together with commentaries on the issues raised by the management and online discussion from relevant experts and the patient's parents.

doi 10.1136/bmj.38951.494028.68

A no-win situation

Having recently started in a new hospital as a medical registrar, I was keen to make a good impression. My first on call fell right in the middle of the busy winter period. Patients were coming at us from all directions, and queues were building up. As a further incentive to stay on top of things, the registrar on night duty, my relieving angel, was a friend of mine. I'd never worked with her before, and I certainly didn't want to leave lots of work behind.

Sleeves up and on with the job. As the hours passed, I rushed around reviewing patients and then, as I caught up with the workload, clerking patients, cannulating, taking observations, etc. By the time the 9 pm handover arrived, I was absolutely exhausted, mentally and physically, but—and this was the important bit—there were no patients waiting to be seen, clerked, or reviewed. Success!

I announced the good news to my colleague and stepped back waiting for the appreciation and admiration. She simply responded, "So, you've had a quiet day." I almost collapsed.

It was then that I realised that I was truly in a no-win situation. If I'd left lots of patients to be seen the natural conclusion would have been that we'd been slacking during the day and had probably been sitting around drinking cups of tea. Of course, when we'd done everything then it was presumed we'd not had many admissions.

Still, I suppose it is better to have tried and failed than never to have tried at all.

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We welcome articles up to 600 words on topics such as *A memorable patient, A paper that changed my practice, My most unfortunate mistake,* or any other piece conveying instruction, pathos, or humour. Please submit the article on http://submit.bmj.com Permission is needed from the patient or a relative if an identifiable patient is referred to. We also welcome contributions for "Endpieces," consisting of quotations of up to 80 words (but most are considerably shorter) from any source, ancient or modern, which have appealed to the reader.