First Person Account: Schizophrenia

by Robert Bayley

The article that follows is part of the Schizophrenia Bulletin's ongoing First Person Accounts series. We hope that mental health professionals—the Bulletin's primary audience—will take this opportunity to learn about the issues and difficulties confronted by consumers of mental health care. In addition, we hope that these accounts will give patients and families a better sense of not being alone in confronting the problems that can be anticipated by persons with serious emotional difficulties. We welcome other contributions from patients, ex-patients, or family members. Our major editorial requirement is that such contributions be clearly written and organized, and that a novel or unique aspect of schizophrenia be described, with special emphasis on points that will be important for professionals. Clinicians who see articulate patients, with experiences they believe should be shared, might encourage these patients to submit their articles to First Person Accounts, Division of Clinical and Treatment Research, NIMH, 5600 Fishers Lane, Rm. 18C-06, Rockville, MD 20857.—The Editors.

I am 28 years old and have suffered from schizophrenia for most of my life. This has resulted in long periods of hospitalization and numerous forms of treatment, many of which just managed to keep me alive. I now live in the community and attend various outpatient clinics where I see the consultants responsible for my care.

Schizophrenia is an extreme of the human condition and is shrouded by enigma and mystery. It is marked by profound misery and isolation and also by societies' neglect and misunderstanding. The inevitable consequence for most victims is that of institutionalization or, as is more common currently, existence within the community. It is often the case that there is insufficient care or support, and many sufferers are left to meander in wretched desolation, treated only with disdain and abuse.

Yet, how does this disorder relate to common perception? Without doubt, it generates misconceptions and fear and is often considered indicative of true "madness." This perception, however, can only perpetuate and augment the alienation that is prevalent in those who are afflicted.

The reality for myself is almost constant pain and torment. The voices and visions, which are so commonly experienced, intrude and so disturb my everyday life. The voices are predominantly destructive, either rambling in alien tongues or screaming orders to carry out violent acts. They also persecute me by way of unwavering commentary and ridicule to deceive, derange, and force me into a world of crippling paranoia. Their commands are abrasive and all-encompassing and have resulted in periods of suicidal behavior and self-mutilation. I have run in front of speeding cars and severed arteries while feeling this compulsion to destroy my own life. As their tenacity gains momentum, there is often no element of choice, which leaves me feeling both tortured and drained. I also hear distorted sounds that modulate and contort from the very core of my brain. There are

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times when these sounds can erupt from nowhere as the voices continue to propel me into a crazed inner world.

The visions are extremely vivid, provoking fear and consternation. For example, during periods of acute bombardment, paving stones transform into demonic faces, shattering in front of my petrified eyes. When I am in contact with people, they can become grotesquely deformed, their skin peeling away to reveal decomposing inner muscles and organs. Buildings and rooms spin and weave and their walls close in as I look on, paralyzed by fear. Inanimate objects take on a life of their own, pulsating and gyrating as linear beams of light cross my visual path. I am powerless to resist the frenzied subjection of alien beings as steel bars are suspended from the ceilings trapping me like a caged beast. There can seem little hope for respite or likelihood of relief. The mind and body become fatigued, which often leads to long periods when I am cut off from the world at large. The visual and auditory onslaught takes its toll, for these experiences push one to extremes.

All these symptoms are typical of many sufferers. Strange thoughts, or "delusions" (as they are described by psychiatric professionals), are also common. What must be remembered is that they are reality to the individual, even if they appear to be unintelligible. Untold damage can be caused by ignoring or trivializing their content. There is often a link with an outwardly recognizable concept or event when time is given to try and interpret the thought processes involved. When regarded as just bizarre or symptomatic of the illness and not treated with appropriate validity, the intrinsic states of withdrawal are often exacerbated. This feeling of being distanced from people and society produces many associated difficulties. Social interaction can become more and more sporadic and behavior increasingly disturbed as the sufferer loses contact with any sources of stability. There is also a danger that a person's gifts or abilities can be misconstrued, particularly if they are in the creative field. But it is unequivocal that many sufferers possess a florid and fertile mind and can generate things of profound beauty, in the fields of poetry or the visual arts for example. Our talents are often not fully appreciated because of stigmatization. Despite this general lack of appreciation, our strengths are evident to those who strive to understand.

It is crucial to state that while schizophrenia is a diagnosis that does cover a specific range of symptoms, the way that it affects the victim is totally individual. The illness is a neurological disease and manifests itself by insidiously feeding on and accentuating the sufferers' inherent personality flaws, distorting them into a shattered form of tangled complexity. Similarly, the disease can break down any strengths, often leaving behind only a fragmented shell. However, it is critical to be aware that the path schizophrenia pursues is particular to each person afflicted. Frequently, there is no attempt made to explore beyond the illness. It is often forgotten that there is a person behind the condition, with a fundamental need to be understood. Because of this, I can feel a profound psychological separation, which extends to the perimeters of my life, and this feeling is shared by many others. Our needs center on being treated with empathy and insight, with our personal characteristics recognized as unique and distinctive in their own right.

The treatments available to those with schizophrenia consist mainly of medicinal therapy, such as the use of neuroleptic drugs. My experience with these drugs is mixed. While they can alleviate some of the more severe symptoms, they often leave the sufferer feeling spiritually and emotionally dead. The risk of tardive dyskinesia is great, especially as antipsychotic drugs are still being prescribed in abundance. The side effects commonly affect movement, gesticulation, and articulation. I have found these effects most distressing, and they have resulted in serious social impairment and loss of confidence. I have also been affected by muscular rigidity, involuntary shaking, and the potentially irreversible loss of control of the muscles in and around the mouth and tongue. Ironically, these conditions are often dismissed as being part of the original illness that these medicines were supposedly treating. One of the most frightening aspects of having schizophrenia is losing control of the treatment that you receive. New medicinal advances are being introduced, and some now minimize or remove the risk of tardive dyskinesia. However, they can cause a new range of adverse side effects, some equal concern. It is therefore vital that doctors make their patients as aware as possible of the potential dangers of neuroleptics. We, as sufferers, are often denied the truths behind this "revolution" in treatment for schizophrenia. I have also been given electroconvulsive therapy as a type of "last resort" treatment option. I consider this option to be entirely inappropriate, and it has had a lasting effect on my long- and short-term memory. Others are subjected to behavior-modification programs, such as token economy regimens, that deny their individuality.
Hospitalization is commonplace for those living with schizophrenia, with the duration varying from weeks to a lifetime. However, the emphasis now is on community care, which fails on many levels. This failure is mainly due to the lack of adequate resources but also because of basic misconceptions bred from the faults of the psychiatric system. We, as sufferers, need structure and consistency in our care and support. However, this structure must not be allowed to become so rigid that there is no room left for spontaneity and creativity. Tapping into a mind experiencing the truly extraordinary and to guide it by way of compassion and inventiveness can bring tremendous comfort and relief to the individual. An offer of time and an attempt to understand a particular person's torment and methods of living with the illness, provides positive and practical support. It is not only the mental health services that require further enlightenment, but also society as a whole.

Expression is a vital component in learning to manage this disease effectively. We must be seen as individuals and not regarded as just a collection of symptoms. With the instigation of more constructive approaches and inspired care, our pain and anguish may begin to be contained. Only then will the balance be redressed and societies' ignorance brought to an end.

The Author

Robert Bayley spends his time painting, composing music, and writing. He has held two exhibitions of his oil paintings and has recorded an album of his own music, conveying his hallucinatory experiences. He also has completed a book of poetry and has recently written his first novel. The book describes the effects of schizophrenia on the life of a semi-autobiographical character. Mr. Bayley also has had articles published previously on psychotic illness.