

The Time After

Regina Bellion

After Withdrawal, the Difficulties Begin

Neuroleptics: Haldol

Each individual must make their own decision regarding whether or not they wish to withdraw from psychiatric drugs. It would never occur to me to tell someone else they should withdraw.

I have the tendency to react psychotically in certain situations. Neuroleptics (apparently) protect you from psychosis.

The first time I withdrew from neuroleptics, I didn't yet know that I would have to find something else—something that no one can sell me or that I could buy at the pharmacy.

Now I know what that something is. I have to work hard and exert myself if I want to stay in reality. I constantly have to check myself to make sure that I am reasonably balanced. I must recognize if I feel hurt and find out what has hurt me. I have to notice if I feel sad. I cannot pretend that everything is okay if I have a bad feeling. And I am allowed to have bad feelings. I can trust my own feelings more than the words of others. I cannot act as if I were not a very sensitive person. I cannot conform if something doesn't feel right. Etc.

Since I stopped taking neuroleptics I now have other problems. I am doing better with these. I cannot recommend them to anyone else, however. Everyone must decide for themselves what he or she can handle.

I will write here about my experiences. Of course, I hope that they will be of use to others. That would make me happy.

One can learn something when patients sit together in the hospital ward and struggle with the same questions again and again. I learned the following truism: Whoever has been taking neuroleptics for a long period of time must not just suddenly quit. Otherwise the symptoms will likely reappear quickly. Often even on the first day. And whoosh—you are back in the closed ward. Neuroleptics must be gradually withdrawn.

Just released from the clinic. The doctor said to me that for the foreseeable future I should take neuroleptics, other forms of therapy are not to be considered, and I shouldn't experiment with anything.

Alone at home. Three times a day I count my Haldol drops. I don't do much else. I sit on my chair and stare in the direction of the window. I have no sense of what is happening outside. I find it difficult to move. Nonetheless I am able to get up everyday. I don't notice that the apartment is getting dirty. It doesn't occur to me that I should cook something. I don't wash myself. I don't even ask myself if I stink. My misery progresses—but I don't even notice.

I vegetate behind my neuroleptic wall and I am locked out of the world and out of life. The real world is further from me than Pluto is from the sun. My own secret world is also gone—my last refuge, and I had destroyed it with Haldol.

This is not my life. This is not me. I may as well be dead. An idea has begun to take shape. Before winter comes I will hang myself.

But before that I want to try and see if my life would be different without Haldol. I reduce the number of drops. I take less and less until I arrive at zero.

After one month I am clean. Then I begin to notice how unkempt I am. I wash my hair, make the bed, clean the apartment. I prepare a warm meal. I even enjoy doing this. I can think again.

Of course, I am afraid that I will become psychotic again without medication. So I get some relevant books. In them I find the standard recommendation: For psychotics in the recovery phase it is important to have a clearly structured daily routine in which little emotion is involved. A life on the back-burner protects one from further psychotic episodes.

Something so lukewarm that looks halfway like a daily routine cannot be my life. I don't want a life on the backburner. I don't want to get locked in a hospital again. Psychiatric drugs are not what I want either.

How can I organize my life such that I don't run the risk of becoming psychotic again? And in case I do: How can I avoid letting my neighbors find out and having them call the police?

I have to clear up these two questions first—and quickly. Thank goodness I have friends who are crazy like me. They help me clear this up.

My friends report to me on their psychotic experiences. They talk about fears, dreams, desires. I am afraid to reveal myself. If my friends know more about me they won't want to have anything more to do with me. The others are much more open than I am. I establish a boundary. Beyond this boundary I only have conversations with myself. I let no one look past my boundary. I fear that I will destroy the image others have of me. The furthest corners of my soul are accessible only to myself. There's not supposed to be any far corners. I don't take anyone there to see.

If only I had early-on taken my friends to see the depths of my soul. During my next psychosis when my automatic censor was out of commission, they found out anyway what moves me and what I wanted to hide. Words, images and actions bubbled forth from me uncontrollably and inundated my perplexed friends. A miracle happened. They didn't turn away from me with horror when they glimpsed the anger in me, but instead they organized emergency care so that I was not alone during the psychosis.

When I had been off Haldol for four months the next psychosis began. At that time I did not yet know under which circumstances I react psychotically. I didn't see the psychosis coming and so was unable to prevent it.

One can survive a psychotic phase without a doctor, a hospital, or neuroleptics. I have done it. And I have watched friends do it. I am only describing my experiences. I can only discuss that which I know first hand.

Without medication and without a doctor, the acute phase of my psychosis can be overcome in about a week. After a maximum of ten days the world is familiar again and I grope my way back into reality. At this point I cannot yet handle conflicts with others. But the most necessary daily tasks can easily be accomplished again. Sometimes I am even able to enjoy myself again.

In order to get through a psychotic episode I need:

- a room in which I will not be bothered by others
- a mattress, a cover, an occasional sip of water, a little something to eat (if anything at all)
- a friend who understands my fear because he knows me well and who doesn't resent me for my condition, who stays calm and stands by me until—in my experience after eight to ten days—the world has regained its familiar contours.

An acute psychosis without psychiatric drugs

When my relation to reality becomes shaky, usually it is already too late to prevent the psychosis—I have to get through it. I can no longer observe my situation with a certain distance. A spiraling movement has begun that follows its own laws and cannot be influenced from without. Usually at the beginning the situation is still interspersed with little islands of reality. Standing on one such island, I can still make myself understood. Sometimes this happens unconsciously, without my intention. If one is not heard at this point, or not understood or rejected, then the whole process is accelerated and the islands sink.

A prompt call for help is important. My friends and I have now reached the point where we can ask each other for help. But we still do this too late. By “late” I mean when the person calling can hardly be understood, when he has already swallowed a bunch of sleeping pills, when he is hindered in calling (most likely due to hallucinations), when he is panicking because he realizes that he has hurt himself, or when relatives are there who have become over-excited.

Once my psychosis has reached the acute phase, then I am locked into my own reality. Only occasionally is it possible for me to perceive the actual reality around me for short moments, though it seems to me to be unreal or unreliable.

In this state I can be very active and do things that I later regret. (I am describing this briefly in case any of the readers do not know what it looks like when someone is having what is called in psychiatry an “acute psychosis.”) Violence against others and against oneself cannot be ruled out. The greater

the fear is, the more the aggressiveness builds. The destruction of things and oneself are common in my experience. The person experiencing the psychosis no longer knows that he had asked for help, or for other reasons he may not be able to open the door for those who have come to his aid.

Of course he would like to share what is happening inside him. In the last few hours or days he has participated in extremely important and strange things. Perhaps he will tell of intrigues against him and their origins, which he has finally grasped. Or he has just experienced something incredible that would take your breath away. He is in a type of time centrifuge in which experience happens at high speeds and nothing is predictable. He can go on about this for hours. We try not to encourage him to do so. He can tell all about it later, but now is not the time.

But you have to take him seriously. Answer his questions so that he can orient himself and approach reality again. You won't help him by pretending that everything is just fine.

The most reasonable thing to do is to radiate calm. It is very important that the person begins calm, steady breathing and finally lies down.

It must be determined if and when the person has reestablished a connection to reality for short moments. Those are the moments in which he listens and understands what we say to him quietly and calmly. At this time his behavior can be influenced. Such moments are the best time to encourage steady breathing. This is important because only then can the panic subside. (Panic can bring on hallucinations.)

These short moments of clarity are the islands of reality in the sea of a psychosis. One can rely on these islands of reality. One can make use of them (something that apparently only a few people are aware of). These islands of reality always return. No matter how bad the situation is, the next reality island is on the horizon! It is the sole responsibility of the helper to see if and how the islands can be used. The more comfortable and anxiety-free the person feels on his reality islands, the more the islands grow in size and number. Reality islands appear even to those who have raged for days and nights without sleep and ransacked the apartment and thrown dangerous objects. It is good if someone helps him to step up onto these islands. Even the most terrible psychosis has reality islands. Once arrived at such an island, one asks a

question or recognizes someone nearby. Even those who speak schizophrenically can be conversed with occasionally.

We have never seen a case where it has taken more than a few minutes for a so-called acute psychotic to accept an embrace or the suggestion of lying down. Lie down next to him. Make sure your body is very close to his. But be absolutely sure that this is what he wants. Avoid any obtrusiveness. Your calm, steady breathing will make him calm. If you are not that intimate with each other, just sit down next to him and hold his hand. That alone can work wonders.

Above all, the person needs peace and quiet, a reliable and kind environment, and the assurance that the helper will stick to the agreements made. It may be that the helper or close friend will occasionally not be appreciated or even suffer physical assault. It is possible that the helper will be rejected. An appropriate helper is someone whose presence does not make the person uncomfortable and who is currently at peace with himself and can keep calm.

The alternation of periods of tumult brought on by the person with a psychosis and the periods of calm effected by the helper can last eight to ten days. In my experience, the psychosis is over after this period of time. It may be two or three weeks until the psychotic associational thinking has faded away. Whoever gets to the bottom of his psychotic experiences afterwards obviously does not run into the next psychotic phase all too soon.

During my acute phases it is senseless to try to bring on sleep with sleeping pills. They don't do any good during this time. Even a high dose of prescription sleeping pills do not induce sleep. A psychosis that has reached the acute phase seems to have its own dynamic, like a dream that may be influenced by outside circumstances but still has to be dreamed to its conclusion.

A relaxing deep sleep is not possible as long as the psychotic "film" is running. If I am able in an acute phase to lie down often and relax my body then I am sometimes able to fall into a light sleep (like most dogs) that allows me to recover a bit. Once you know from experience that sleep will come again after a week or so, then this topic is no longer so disturbing.

To avoid misunderstandings, let me differentiate the terms. An "acute phase" is not the time during which a world of delusions is being built up, during which I am still well able to grasp the reality around me. An "acute

phase” is the relatively brief period during which I can only sporadically perceive reality.

Just as a person can fall back into a psychosis, it is also possible for him to look toward reality if this seems worthwhile. The tendency to one or the other of these possibilities can be influenced by the person himself or his environment, though not at all times nor to the extent we would hope for.

During the acute phases of my psychosis, it was not good for me to be alone. Constant presence quiets not only the person experiencing the psychosis but also the fears of the helper.

The fear of the helper is not without reason. Even after ten episodes that ended fine, a bad ending could be next. In certain grim, long moments hope evades us because no one can guarantee that a so-called borderline patient will fall asleep each time within six hours. Any one time it could be different. For *me* as an acute patient, not calling a doctor means a lapse in getting the appropriate help. If I am left alone even briefly I may slit my wrists during my madness.

The helper’s fear will often be hushed by the person suffering the psychosis. He will suddenly want to know what day of the week it is. He has landed on a reality island for a moment and says: It’s good that you’re here. He asks: How long did it last for you last time? Then the voices come again from the corners of the room, and the person doesn’t recognize you any more. He thinks he has to kill himself or you, or he thinks he is a baby or that the world is breaking in two. You should lie down next to your friend and breath deep in order to calm him.

The experiences you have now will give you confidence during the next psychotic phase—even your own. That is, if you have another at all. Who can prophesy this?

For months I had not taken any more neuroleptics. I had stopped visiting the psychiatrist long ago. I dared to leave the questionable care of traditional psychiatric institutions. My friends and I tried to help one another. But we weren’t sure that this would work. It was just the beginning for us. We were afraid when we arrived to help each other. We had little experience and we were not familiar with the dynamics that lie at the heart of every psychosis.

Each one we got through together was like a strange, dangerous, solitary journey outside the law. We would not have been able to explain to anyone what we were doing. We didn't even know ourselves. We hardly spoke about the exceptional circumstances that we experienced together.

But I knew approximately what I was risking with this solitary route. I could wind up committing suicide, or I could land in a closed ward by accident, or in a ward for chronic patients, or I could become so aggressive that I end up as a hopeless forensic case. Or I could quickly begin taking psychiatric drugs again and avoid all that. Or I would have to use my own strength to stay balanced. I decided upon the last option. At least I wanted to try it that way.

A psychotic episode doesn't just fall from the sky. I began to understand this. I had observed it in my friends. This must surely be the case with myself as well, but I could see it more immediately in others. An episode has its causes, it builds up. The course of its building up can be retroactively reconstructed. Therefore, it must also be observable at the time.

I drew conclusions. The circumstances prior to a psychosis lead into the psychosis and must therefore be interpreted as warning signals. The earlier these circumstances are detected, the earlier the warning can be taken seriously, the better the prognosis. Today I know that it doesn't always have to come to a psychosis.

I have to keep an eye on my condition and to name that condition so that I know how I'm doing and what I need to change. If I am questioning whether or not I can trust my perception it is probably already too late.

I try to observe myself from a certain distance in order to track those disquieting changes in myself early on. If I become sensitive to noises, for example, that is an alarm signal. If I am up all night working on something, that's also a sign. If I feel like I want to withdraw from the world for a long time that is less a sign of being balanced than of being on the way to an extreme position. If I am constantly on the move and cannot be alone, that's just as bad. I try to stay in balance. I struggle with it every day. And sometimes I have little time for anything else.

An example: Excitability and activity, paired with euphoria, can be diminished or stopped. If I don't take account of my excitability, activity and euphoria, this condition can grow into a mania. And then I am no longer in a

position to determine how I am doing or if things are alright. Mania can seamlessly evolve into a psychosis. If my excitability has reached a certain degree, the wise thing to do is to lie down on the sofa and to think about my situation. I try to account for the condition I am apparently in. I breath calmly and deeply and remain lying down. I don't answer the phone. I do nothing or after a few hours of peaceful rest I take a walk. (This kind of self-treatment doesn't help anymore with a well-developed mania. I must recognize immediately how I am feeling.)

There are techniques (gymnastics, breathing exercises, posture) for influencing and changing your condition. Everyone must discover the techniques appropriate for him or herself. This is not something that can be done quickly in one's spare moments. It takes time and energy to develop one of these techniques into an aid that can be promptly utilized.

An example: As quickly as I can bring myself into a stressful state with quick, short breaths, I can also bring myself into a peaceful state with calm, deep breaths. Or if I constantly slink around with my head low, then it is no wonder that my mood will become depressed. Such simple things are not a panacea. But they have effects that I can make use of.

When I was trying out new things, I came upon a catalog of preventative measures. These measures are nothing special. But they are of use to me. Many of my friends have also been able to help themselves with them.

Taking precautions

We have found it useful to create a partially structured daily routine that is not full of duties and boredom. Regular meals are important, enough sleep, and—if necessary—fragrant baths. Many people who occasionally react psychotically are night people. If I find myself being a night owl for a long period of time, I can more easily fall out of reality. At night it is important to keep breathing regularly and not to breath too flatly or to hold your breath unintentionally. Abdominal breathing can be very painful at first or induce a fit of crying. It is important to avoid situations that become hectic. I am now in a position to walk away from situations that are too stressful for me.

When emotions whirl around me, I am in danger of a psychosis. You can't avoid twists of fate. Instead of giving in to temptation or withdrawing in an

emergency situation, we need contact with friends more than ever. Contact with people who take us seriously, but to whom we have no great emotional relationship, is also important. With their help we can test whether or not we still have one foot in reality. This is a touchy subject that we constantly have to watch out for. Many people who occasionally react psychotically have been so hurt that they have become over-sensitive. They withdraw from others.

One must particularly watch out when falling in love. In a love relationship there is a great danger of my being hurt in the way that I was earlier as a child. If early traumas are called forth again, I can easily react with a psychosis.

Of further importance is having a task, some kind of work, an activity that we experience as meaningful. Each individual must find their own appropriate type of activity. (It is irrelevant what others think of this activity.) It is important and very freeing to let go of the idea that one must represent an image of normality. It is important to live out one's individuality and give expression to it—even if it is unconventional.

It is never wrong to ask oneself on relatively healthy days what it was that spurred the recent hallucinations. Ways in which we can work against tricks of the senses are described in a book by the psychotherapeutically-oriented psychiatrist Silvano Arieti (Arieti 1979, pp. 109ff.).

And of course everything possible must be done to establish and to stay in contact with one's own body. Foot reflex zone massages, jogging, T'ai Chi, belly dancing—everything can be of use, or not. (Caution: T'ai Chi can be dangerous for people who have knee problems.) It is worth it to keep searching and experimenting until you can feel your own body again. This feeling has to be reestablished every day.

Particularly important to me has been to avoid building up networks of associative ideas, but instead, if necessary, to ask others from the waking life to describe from their perspective the relations that seem suspicious to us. We people with the diagnosis of a "psychosis" apparently did not have the chance to develop a basic feeling of having a satisfying identity and a corresponding self-confidence. Thus we must care for ourselves particularly well and devote much attention and time to ourselves. It is not enough to finish one's studies or to achieve some kind of success that is universally admired.

These are the common maneuvers of self-deception that have little to do with inner satisfaction. The feeling of being worthy comes to me more readily when I take time to dream and lie in the bathtub. Others find their peace by playing guitar or writing in their diaries.

The most important thing is to recognize altogether contradictory behavior (so-called double-bind situations) early enough and to back away. Absurdities, disrespect and double-bind messages hurt us and make us crazy.

An assertion: my psychosis is not senseless

There are important points in life that make changes necessary. Or a change in your attitude to life becomes necessary. Sometimes a new orientation is called for, a new beginning with largely unknown starting conditions cannot be averted. The fact that things have gotten to a critical point is often preferably swept under the carpet.

A critical point can be for example entering adulthood. Or an exam period. If a person we love leaves us, a crisis can ensue. There are few rituals in our culture that help us to regain strength during a crisis or at least give us the feeling that we are not alone.

People who react psychotically in such situations are usually given psychiatric drugs and kept in the loony bin until they can create the impression that they are once again conforming. Then they are released back into the same unchanged situation that had brought on the crisis. Thus the next "episode" is already programmed. For some the situation is different. But this is exactly what my experience has shown me. Established clinical psychiatry does not grant the experience of psychosis much regard, and it doesn't find that a psychosis can be of use. "It's all chaos without any meaning," said the doctor at the state hospital.

I am of another opinion. When I have gotten through a psychosis, I cannot pretend that nothing has happened. I have to work through my psychotic experiences; they hold meaning for me. The psychotic "films" are grounded, they relate to me and my life. They are a mirror and a message for me, like my dreams at night. I must take my psychosis seriously just like others do with a heart attack. I must pay attention to the signal that my psychosis emits. If I don't want to do this, if I can't or don't, then I shouldn't be surprised at the

next “episode.” (Of course I can only speak for myself. If someone else sees this differently, then he or she has their reasons.)

In a psychosis there are more or less encoded images of destruction and new beginnings. That is no secret. Someone who does not see the possibility of change and a new beginning after a psychosis, or who cannot reorganize their life, does not want to develop into a new phase of life, or who first becomes depressed—he or she could possibly be helped through these stages with alternative psychoactive medicine. This is exactly what I did earlier—take psychoactive drugs, that is, psychiatric drugs—and I could do it again.

Once again I was done with this world. This time it was clear to me that I had nothing to lose. I had skidded past death and through insanity—what else could possibly happen? I felt I could risk something new. What that new thing would look like, I certainly did not know.

I still don’t know. But since October 1993 I haven’t had another psychosis, I haven’t killed myself, and since the summer of 1993 I have done well without psychoactive drugs. That is not such a long time. It is hardly worth mentioning. But for me it is amazing.

Translation from the German by Christina White

Erwin Redig

A Mental Struggle

How I Stopped the Use of Psychiatric Drugs

Neuroleptics

When I was in the psychiatric hospital, there was an old man who was always drawing birds with colored pencils. He did this on his own, in a corner at a table, after the hours of therapy. I believe that the therapists did not even notice this little expression of his creativity. One day I went to the man and asked him if I could buy one of his drawings. These were not perfect, but to