

Confessions of a Noncompliant Patient

by Judi Chamberlin

A famous comedian once said, "I've been rich, and I've been poor, and believe me, rich is better." Well, I've been a good patient, and I've been a bad patient, and believe me, being a good patient helps to get you out of the hospital, but being a bad patient helps to get you back to real life.

Being a patient was the most devastating experience of my life. At a time when I was already fragile and vulnerable, being labeled and treated only confirmed to me I was worthless. It was clear my thoughts, feelings, and opinions counted for little. I was presumed not to be able to take care of myself or to make decisions in my own best interest, and to need mental health professionals running my life for me. For this total disregard of my wishes and feelings, I was expected to be appreciative and grateful. In fact, anything less was taken as a further symptom of my illness, as one more indication I truly needed more of the same.

Trying to Be a Good Patient

I tried hard to be a good patient. I saw what happened to bad patients—they were the ones in the seclusion rooms, who got sent to the worst wards, who had been in the hospital for years, or had come back again and again. I was determined not to be like them. So I gritted my teeth and told the staff what they wanted to hear. I told them I appreciated their help. I told them I was glad to be in the safe environment of the hospital. I said that I knew I was sick, and that I wanted to get better.

In short, I lied. I did not cry and

scream and tell them that I hated them, their hospital, their drugs, and their diagnoses, even though that was how I really felt. I had learned where that kind of opinion got me—that was how I ended up in the state hospital in the first place. My diagnosis was chronic schizophrenia; my prognosis was that I would spend my life going in and out of hospitals.

I had been absolutely outraged during my first few hospitalizations in the psychiatric ward of a large general hospital, and in several supposedly prestigious private hospitals. I hated the regimentation, the requirement that I take drugs that slowed my body and my mind, the lack of fresh air and exercise, and the way we were followed everywhere. So I complained, I protested, I even tried running away. And where had it gotten me? Behind the thick walls, barred windows, and locked doors of a "hospital" that was far more of a prison than the ones I had been trying to escape from. The implicit message was clear—this is what happened to bad patients.

Playing the game

I learned to hide my feelings, especially negative ones. The very first day in the state hospital, I received a valuable piece of advice. Feeling frightened, abandoned, and alone, I started to cry in the day room. Another patient came and sat beside me, leaned over and whispered, "Don't do that. *They'll* think you're depressed." So I learned to cry only at night, in my bed, under the covers, without making a sound.

My only aim during my 2-month stay in the state hospital (probably the

longest 2 months of my life) was to get out. If that meant being a good patient, if that meant playing the game, telling them what they wanted to hear, then so be it. At the same time, I was consumed with the clear conviction that there was something fundamentally wrong here. Who were these people who had taken such total control of our lives? Why were *they* the experts on what *we* should do, how *we* should live? Why was the ugliness, and even the brutality, of what was happening to us overlooked and ignored? Why had the world turned its back on us?

So I became a good patient outwardly, although inside I nurtured a secret rebellion that was no less real for being hidden. I would imagine a future in which an army of former patients marched on the hospital, emptied it of patients and staff, and then burned all the buildings to the ground. In my fantasy, we joined hands and danced around this bonfire of oppression. You see, in my heart I was already a very, very bad patient!

The Issue of Drugs

One of the things I had already discovered in my journey through various hospitals, which culminated in my involuntary commitment to the state hospital, was that psychiatric drugs did not help me. Every drug I was given made me feel worse, not better. They made me fat, lethargic, unable to think or to remember. When I could, I refused drugs. Before I got committed, I used to hide the pills in my cheek, and spit them out when I was alone. In the state hospital, however, I did not

dare to try this trick. I dutifully swallowed the pills, hating the way they made me feel, knowing that, once I was free, I would stop taking them. Once again, I was noncompliant in thought before I could be noncompliant in deed.

Respecting choices

Now, I want to make one thing very clear—I am not advocating that psychiatric drugs not be taken. What I am saying is that each individual needs to discover for him- or herself if the drugs are part of the solution or part of the problem. Many people I know—and respect—tell me that they would not be where they are in their recovery were it not for the particular drugs that they have found work for them. On the other hand, many others, of which I am one, have found that only when we clear ourselves of all psychiatric drugs do we begin to find the road to recovery. We need to respect these choices, and to understand that there is no one single path for all of us.

Psychiatric drugs, like all drugs, have side effects. If the positive effects outweigh the negative effects, then people will generally choose to take the drugs. When the negative effects, however, outweigh the positive ones, then the choice to not take the drugs is a good and reasonable one. Side effects can be more easily tolerated when one is gaining something positive in return.

A cost/benefit ratio

Let me give an example from my own experience. Every day, I take anti-inflammatory drugs to control the symptoms of arthritis. Without these drugs, I would be in pain much of the time, and find it difficult to move easily. I am willing to put up with the danger of developing ulcers (I take another drug to help protect my stomach), because the

cost/benefit ratio works out in my favor. If, on the other hand, the anti-inflammatory drug did not relieve the arthritis pain, the cost/benefit ratio would go the other way, and I would stop taking the drug and discuss with my rheumatologist another approach to try.

Making informed choices

Here is the key difference between what happens to psychiatric patients and what happens to people with physical illnesses. With my rheumatologist and my lung doctor (I also have a

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chronic lung disease), I am a full partner in my own treatment and recovery. I am consulted, listened to, and given the information I need to make informed choices. I acknowledge that the doctors have expertise that I lack, and they, in turn, acknowledge that I have information about the workings of my own body needed to guide them in their recommendations. Sometimes we disagree, then we talk about it. Sometimes I take their advice, while other times I do not.

We psychiatric patients, on the other hand, are usually assumed not to know what is best for us, and to need supervision and control. We are often assumed to be talking in code; only so-called "experts" can figure out what we "really" mean. A patient who refuses psychiatric drugs may have very good

reasons—the risk of tardive dyskinesia, for example, or the experience of too many undesirable negative effects. But professionals often assume that we are expressing a symbolic rebellion of some sort when we try to give a straightforward explanation of what we want and what we do not want.

I am sure you have heard the many psychiatrist jokes that feature the punch line, "Hmmm, I wonder what he meant by that?" Well, doctor, I want to tell you, we usually mean just what we are saying. In the slogan of the women's movement: "What part of 'no' don't you understand?"

Recovery—A Goal for Everyone

I consider myself a very lucky person. I do not think that I have some special talent or ability that has enabled me to recover when so many others seem stuck in eternal patienthood. I believe that recovery is for everyone. In the words of the mission statement of the National Empowerment Center, we:

"carry a message of recovery, empowerment, hope, and healing to people who have been diagnosed with mental illness. We carry that message with authority because we are a consumer-run organization and each of us is living a personal journey of recovery and empowerment. We are convinced that recovery and empowerment are not the privilege of a few exceptional leaders, but rather are possible for each person who has been diagnosed with a mental illness. Whether on the back ward of a state mental institution or working as an executive in a corporation, we want people who are mental health consumers to . . . regain control over their lives and the resources that affect their lives."

Holding on to dreams

One of the elements that makes recovery possible is regaining belief in oneself. Patients are constantly indoctrinated with the message, explicit or implicit, that we are defective human beings who should not aim too high. In fact, there are diagnostic labels, including "grandiosity" and "lack of insight," to remind us that our dreams and hopes are often seen as barriers to recovery instead of one of its vital components.

Professionals and patients often have very different ideas of what the word "recovery" means. Recovery, to me, does not mean denying my problems or pretending that they do not exist. I have learned a lot from people with physical disabilities, who think of recovery not necessarily in terms of restoring lost function, but of finding ways to compensate or substitute for what one may be unable to do.

Some of the most able people I know, in the true sense of the word, are activists in the physical disability movement—they may not be able to see, hear, or move their limbs, but they have found ways to do the things they want to do despite these difficulties, and despite those professionals who may have advised them not even to try. Without our dreams, hopes for the future, or aspirations to move ahead, we become truly "hopeless cases."

The Trap of Being a "Good Patient"

I often hear professionals say that although they support the ideas of recovery and empowerment in principle, it just will not work for *their* clients, who are *too* sick, *too* disabled, *too* unmotivated. Whenever I hear these objections, I want to know more about what kinds of programs these professionals work in, and what goes on there. I know the professionals who knew me as their patient thought the

same things about me. That is the dilemma of the "good patient."

A good patient is one who is compliant, who does what he or she is told, who does not make trouble, but who also does not ever *really* get better. A "good patient" is often someone who has given up hope and who has internalized the staff's very limited vision of his or her potential.

Now, again, I want to make myself clear. I am not saying that mental health professionals are evil people who want to hold us all in the grip of permanent patienthood, and who do

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not want us to get well. What I am saying is that there is something about being a "good patient" that is, unintentionally perhaps, incompatible with recovery and empowerment.

When many of us who have become leaders in the consumer/survivor movement compare notes, we find that one of the factors we usually have in common is that we were labeled "bad patients." We were "uncooperative," "noncompliant," "manipulative," or "lacked insight." Often, we were the ones who were told we would never get better. I know I was! But 25 years of activism in the consumer/survivor

movement has been the key element in my own process of recovery.

Strong and assertive versus compliant

Let us look at this word "compliant." My dictionary tells me it means "acquiescent," "submissive," "yielding." Emotionally healthy people are supposed to be strong and assertive. Slaves and subjects must be compliant. Yet compliance is often a high value in professionals' assessments of how well we are doing. Being a good patient becomes more important than getting well.

It is similar to the healthy woman/healthy person dilemma. Psychological researchers have found that although emotionally healthy adults, gender unspecified, are supposed to be assertive and ambitious, emotionally healthy women are supposed to place the needs of others before their own. If you are a woman and fulfill the stereotyped "woman's role," then you are not an emotionally healthy person. If, on the other hand, you are strong and assertive, then you can be labeled as not being an emotionally healthy woman.

Getting better, we were informed by staff, meant following their visions of our lives, not our own. Let me give an example, from a book called *Reality Police* by Anthony Brandt:

"I was thought to be a hopeful case, so the doctor assigned to it worked up a life plan for me . . . I was to stay in the hospital 3 months or so to stabilize my life, she said. When I seemed up to it, I would go to work in the hospital's "sheltered workshop" where I would make boxes for IBM and be paid on a piecework basis. When I had made enough boxes, I would then be moved to the halfway house in Kingston, across the Hudson, where they would arrange a job for me in a

special place called Gateway Industries established for the rehabilitation of mental patients. There I would presumably make more boxes. Eventually I might move out of the halfway house into my own apartment."

What Anthony Brandt's doctor did not know was that Brandt was not a "mental patient" at all. He was a writer who had feigned the symptoms of mental illness to find out first hand what the life of a mental patient was like. He had a successful career and a real life that he could return to. He did not have to accept this limited view of his abilities and his potential. Most real mental patients are not so lucky.

Anthony Brandt wrote his book in the mid-1970s, but what happened to him unfortunately continues to happen. All those "unmotivated clients" I continue to hear about are the ones who are on a silent sit-down strike about others' visions of what *their* lives should be like. When I ask professionals what it is that their clients are "unmotivated" about, it usually turns out to be washing floors or dishes, on the one hand, or going to meaningless meetings on the other. Would you be "motivated" to reveal your deepest secrets to a stranger, for example, someone you have no reason to believe you can trust with this sensitive information? And, more important, *should* you be "motivated" to do so?

Hope—Essential for the Human Spirit

People, in general, are motivated to do things that they want to do, or that will get them things which they want. Just because someone has a diagnosis of "mental illness" does not change that fundamental fact of human nature. All the time and energy that mental health professionals seem to put into "motivat-

ing" their clients to do things they do not want to do would, I think, be better spent helping clients to figure out what things they want for themselves, and the strategies to achieve them.

We need to start encouraging people to dream, and to articulate their own visions of their own futures. We may not achieve all our dreams, but hoping and wishing are food for the human spirit. We—all of us—need real goals to aspire to, goals that we determine, aims that are individual and personal. I feel crushed when I visit programs that train their clients for futures as residents of

Recovery should mean finding ways to compensate for what one may be unable to do.

halfway houses and part-time workers in menial jobs. And if I, a visitor, feel my spirit being crushed, how do the people trapped in those programs feel?

Researchers have asked clinicians what kinds of housing, for example, their clients need, and been told that congregate, segregated housing was the best setting. At the same time, the researchers have asked clients directly what kind of housing they want, and been told that people would choose (if they were given the choice) to live in their own homes or apartments alone or with one other person they had chosen to live with. At the end of a year, the researchers found, the clients who got the type of housing they wanted were doing better than the clients who

got the housing that was thought to be clinically appropriate. Helping people reach their goals is, among other things, therapeutic.

A high price to pay

One of the reasons I believe I was able to escape the role of chronic patient that had been predicted for me was that I was able to leave the surveillance and control of the mental health system when I left the state hospital. Today, this is called "falling through the cracks." Although I agree that it is important to help people avoid hunger and homelessness, such help must not come at too high a price.

Help that comes with unwanted strings—"We'll give you housing if you take medication," "We'll sign your SSI papers if you go to the day program"—is help that is paid for in imprisoned spirits and stifled dreams. We should not be surprised that some people will not sell their souls so cheaply.

Let us celebrate the spirit of non-compliance that is the self struggling to survive. Let us celebrate the unbowed head, the heart that still dreams, the voice that refuses to be silent. I wish I could show you the picture that hangs on my office wall that inspires me every day, a drawing by Tanya Temkin, a wonderful artist and psychiatric survivor activist. In a gloomy and barred room, a group of women sit slumped in defeat, dressed in rags, while on the opposite wall their shadows, upright, with raised arms and wild hair and clenched fists, dance the triumphant dance of the spirit that will not die.

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