

Learning to Live With Schizoaffective Disorder: A Transformative Journey Toward Recovery

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I have endured auditory and visual hallucinations, paranoid thoughts, and depressive symptoms since the age of 6 (some 40 years ago), and was formally diagnosed with schizoaffective disorder, depressive type in young adulthood. I chose not to surrender to my illness, but instead to wage a war against my symptoms. And I felt that I was winning that war until I chose to leave a successful but stressful career (built over a period of 25 years) to restore my health and my quality of life.

I now believe that my psychotic symptoms are a response to unfortunate childhood events, and feel that I have been able to consistently function at a high level despite my symptoms because of my innate intelligence, my internal drive, my stubborn nature, and the impact of a handful of special people who have empowered me, since adolescence, to believe in myself and to solve my own problems.

Schizoaffective disorder usually presents as a continuous psychotic illness punctuated by intermittent symptoms of either depression or bipolar disorder. I was not medicated for psychosis until after I had been treated with tricyclic antidepressants for several years, and although I am clearly clinically depressed at times, distinguishing between my depressive symptoms (which include anhedonia, hopelessness, and active social avoidance) and the negative symptoms associated with my psychotic illness (which include flat affect, emotional withdrawal, passive social withdrawal, and avolition) is more of an art than a science. I also experience vivid positive symptoms, including paranoid thoughts and auditory and visual hallucinations, but interestingly, because I have never not been able to reality-test, I am not burdened with the disordered thinking and speech that generally associated with a formal thought disorder. I am, however, increasingly challenged by cognitive deficits, including difficulties with my working memory and visual memory, which I find particularly distressing because of the impact that this illness-associated decline may have on my ability to continue to function at a high level.

My childhood was remarkable for my mother's emotional abuse, which stopped when I chose to leave her house

at the age of 12. I was fortunate in that I had a safe place to go, where I encountered tough but genuine love and limited but appropriate rules. In my new home, I was asked how I felt (and not what I had done or how I had performed), and I was encouraged to accept who I was (and not who someone else wanted me to be). And perhaps of greatest importance, I was helped to believe in myself despite rapidly intensifying depressive and psychotic symptoms.

Although I was able to leave my mother's abusive behavior behind, her voice followed me: soon after leaving her home, I became aware that I was hearing multiple critical and hostile voices that no one else could hear. Not unlike the abuse, the voices perpetually torment and humiliate me. For instance, while recently relaxing on my bed with my cats, my voices said, "Why are you relaxing? You don't deserve to enjoy yourself—not when you can't get anything else done. You are useless. You're worth nothing—less than nothing."

Because of the chronic nature of my symptoms, I was told over 25 years ago by an inpatient psychiatric social worker that I would never be able to live or work independently. Nonetheless, I have always been able to thought-stop and reality-test, and these coping skills allowed me to establish an intellectually challenging career helping others that I was able to sustain for over two decades. But I have recently learned that failing to acknowledge my psychotic symptoms—especially my auditory hallucinations—is actually maladaptive, and with the support of my current treatment team, I have resigned myself to the reality that my symptoms are integral to my "recovery" and to who I am.

I believe that I am working toward "recovery," but I still struggle with what that means to me. Does "recovery" mean the relative absence of the symptoms that I have described? Or, rather, the conviction that I can learn to deconstruct the messages associated with my symptoms and to set limits with my symptoms in a way that is both assertive and respectful? Assuming that the latter represents the first milestone in my recovery journey, I believe that I am beginning to learn to work *with* my symptoms and not *against* them—to view my symptoms

as a source of insights into emotions that date back to my early childhood, and to feel grateful for these insights.

My recovery journey has benefited tremendously from my collaborative relationships with the members of my treatment team, some of whom I have known for years and even decades. Their expertise in individual psychotherapy, psychopharmacology, and cognitive behavioral therapy for psychosis has provided me with tools essential to my recovery journey. The cognitive remediation training and dialectical behavior therapy psychoeducation to which I have been exposed have also positively affected my journey to recovery. And although I have never used substances, I do live with several co-morbid medical conditions. My regular primary care visits have demonstrated how important close primary care follow-up can be to continuity and coordination of care.

As I recover, I am also faced with rebuilding my identity and my life. Making the decision to end my career profoundly affected my sense of identity and self-worth, and I have been left since searching for meaning and for a means by which I can continue to help others. Since my resignation, I have struggled with sustained periods of social isolation, which have served to exacerbate my symptoms and to precipitate deterioration in overall functioning.

My initial strategy for change was to take a break from the high-stress activities that have historically triggered symptoms and to, instead focus on “anchoring activities” that I find personally meaningful, intellectually challenging, and conducive to “connectedness” with others. This initial plan—to fully participate in personally meaningful “anchoring activities” that serve to connect me to others—is just being fully realized. I had hoped that my plans to join a clubhouse (a community of people living with psychiatric illness who work together to lead productive lives) would have helped me to feel that I was contributing to a working community—a community that was larger than myself. But after 2 days as a member, I determined that psychiatric rehabilitation in the company of others was not for me.

Just over a year later, I encountered the opportunity to participate in a clinical trial involving a unique intervention to improve motivation in subjects diagnosed with schizophrenia spectrum disorders. I determined then that moving forward in the absence of a supportive community would be near to impossible. In the context of failed attempts to volunteer and to implement “rehabilitative” plans of my own, my experience as a research subject has been especially powerful.

Being connected to something larger than myself—outside of myself—has served, in the past, to give meaning to my life. And I am reminded of the power of connectedness as I struggle to engage in communities of all sorts—especially those that promote a sense of personal agency and self-efficacy. My efforts to participate in a book group and a weight management support group, for example, have not gone unrewarded. Being accepted and valued as

a worthwhile person and an effective human being makes me feel like I am more than my illness.

Restoring connections with members of my family, with my colleagues, and with those whom I helped professionally has been more challenging, however. There was a time when I took those connections for granted. Processing the events that have shattered those connections will be essential as I move toward recovery.

Accepting responsibility for and then learning how to overcome my self-taught barriers to connectedness clearly are critical milestones in my journey to recovery. I believe that I built these barriers at a young age as a survival mechanism—a way of coping in a hostile environment. And as I matured, these barriers grew, seemingly in an effort to protect me from continuing to experience pain. But although I chose to build a career in a “helping” profession, my failure to engage in the complex and intimate relationships characteristic of young adulthood served to stunt my social and emotional growth. I not only lost my sense of connection to others, but also to myself.

Although many of the members of my blended family still welcome me into their lives without judgment, my next challenge became to build the confidence necessary to establish my own “life”—to connect deeply to and be truly intimate with close friends and, ultimately, with a life partner. My life began with the intimacy of birth, but then continued with my dependence on an emotionally abusive mother. Constant criticism is a barrier to intimacy, yet paradoxically represented my mother’s solution to a deep longing to be connected—coupled with a deep fear of being close. Understanding this about my mother’s motivation may help me not to project this learned behavior onto others.

Connecting deeply with others has also meant creating a space that they can visit, and also being willing to come out of that space to visit with them. To do this, I have had to be brave enough to make room for others and humble enough to enter their world when invited. This has required me to tolerate being vulnerable—first, by relinquishing the need to control, and then, and perhaps most importantly, by learning to value someone else’s feelings as much as I value my own. My life’s greatest paradox has been that while I have longed for intimacy, I have feared it greatly, and, until the last several years, felt isolated and alone as a result. Although I have lost touch with most of my friends from high school, college, and graduate school, I have been able to sustain an intimate relationship and a long-term, close friendship.

Ultimately, I believe that recovery can be described as a process, as a vision, and as an outcome. For me, the process of recovery involves changing roles and life goals—it is an intensely personal transformation. My recovery vision is a vision of a life that meets my needs to feel competent, valued, and connected to others. But I acknowledge that recovery as an outcome may not be a symptom-free outcome. My ideal recovery outcome is a life transformed into which I can integrate new meaning and purpose as well as my decades of lived and professional experience.