

Tardive Dyskinesia – Be Your Own Advocate

Tardive Dyskinesia (TD) is a delayed-onset neurological syndrome that can occur as a side-effect of prolonged use of antipsychotic medications. People who develop TD may have repetitive involuntary movements that are generally slow and writhing, or dance-like in nature. The movements occur most commonly in muscles of the face, mouth, and tongue, but can appear in the arms, legs, or torso as well. Estimates of the frequency of TD differ but range from 7%-30% of people who take antipsychotics for a prolonged period.¹ The length of exposure required to develop TD is variable, but it can occur months or even years after starting treatment with an antipsychotic. Once TD manifests, it may become irreversible. Therefore, early detection is critical.

I am honored to be a part of the CURESZ Tardive Dyskinesia Experts Panel, but I haven't always been adept at diagnosing TD. For years, no one in my current practice seemed to have "obvious" symptoms of TD, so I came to assume that it was more of a historical problem associated with the older first-generation antipsychotics that I rarely prescribe. In 2016, I began working with a young man with schizophrenia whose TD was unmistakable. With no FDA-approved medications at the time, the best I could offer was to remove or reduce one of the two antipsychotics he was taking. He and his father wouldn't consider any change, because that combination was the only thing that had ever worked for him. When his father suddenly passed away months later, his grief inspired me to learn as much



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as I could about treating TD. I couldn't give him his father back, but I could at least try to give him the dignity of control over his body.

I studied Neurology journals and textbooks for months and realized that I had unconsciously set my bar for diagnosing TD at only the highest severity level. I had inadvertently become blind to detecting mild to moderate TD. Reading the numerous failed clinical trials of medications and

supplements for treating TD, I gained an appreciation of the decades of powerlessness clinicians had felt in trying to treat TD. It seemed that recognition of TD was gradually overshadowed by increased screening for other potential side effects of antipsychotics, such as blood sugar and cholesterol elevations. Perhaps because the latter are problems for which we have long had good treatment options. In 2017, the FDA approved the first two medications for TD, and treating my patient with one of them benefitted him in profound ways I didn't expect.

Every psychiatric provider trained in an era in which there was little or nothing we could do to address TD, so many didn't have enough urgency looking for it. Our diagnostic skills withered, and many newer clinicians never established proficiency in the first place. Now that approved treatments exist, the mental health field will eventually enhance its recognition of TD, but if I didn't have this unique experience when I did, it might have been years before I stepped up my screening. Until every provider makes a thorough examination for TD a standard part of their appointments, I urge everyone taking an antipsychotic, especially anyone experiencing unusual or unexpected movement problems, to be your own advocate and take the lead in discussing TD with your provider.

Reference: 1. Carbon et al. J Clin Psychiatry 2017;78(3):e264–e278.

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CureSZ
Brain Facts

by Henry A. Nasrallah, MD
CureSZ VP and Scientific Director
**Brain Regions Involved
in Schizophrenia**
Part 1: The Frontal Lobe

Many brain regions are involved in Schizophrenia's signs and symptoms. The frontal lobe is the "command and control" part of the brain, essentially the "Chief Executive Officer" of one's life. The following are clinical features of Schizophrenia attributed to a frontal lobe dysfunction:

- Difficulty in making decisions
 - Concrete thinking, lack of abstraction
 - Difficulty in making decisions
 - Difficulty planning ahead
 - Perseveration and inability to "shift" one's thinking
 - Poor impulse control
 - Apathy, poor motivation and lack of initiative
 - Inability to regulate one's behavior
 - Impaired moral judgement
 - Motor abnormalities
 - Failure to understand or respond properly to social cues
 - Abnormal language
 - Irritability and aggression
 - Lack of insight into one's illness
- (Next issue, Part 2: the hippocampus)

SCHIZOPHRENIA SURVIVORS



Three Pieces of Wisdom to Ensure a Good Place



Ashley Smith,
author, peer counselor, and mother

I was 20 years old when I experienced my first hospitalization. My second and last hospitalization occurred at age 31. During this 11-year gap of hospitalizations I gained much wisdom. When I was first diagnosed with schizophrenia, my doctor gave me two pieces of advice, (1) take your medicine, and (2) manage your stress.

1. Take your Medicine
2. Manage your Stress
3. Create a Post-Crisis Plan

Thanks to these two hospitalizations I regained my life more quickly. I also learned a third piece of wisdom, which is to create a post-crisis plan. I encourage peers in recovery to make plans for the future.

In between my two hospitalizations, as I was recovering, I became better equipped with coping skills. I re-created my personalized Wellness Recovery Action Plan (WRAP) and I found I was finally able to maintain a good place of mental health.

First, at age 20, I did not understand my diagnosis of schizophrenia, or that recovery was possible. In fact, my undiagnosed symptoms led me to encounter both legal issues and my first hospitalization. I was

anxious, afraid, and experienced a wide-range of symptoms including hallucinations, psychosis, delusions and paranoia. My hallucinations frightened me. I did not know what hallucinations were, and thus, could not articulate symptoms. My hallucinations included exaggerated evil cartoon-like voices telling me I was a dishonor to my family. In addition to that, multiple voices clouded my thinking, and disrupted my ability to engage in conversations. Different hallucinations continued to scare me. I believed the same person was stalking me, which I could not outrun nor escape. Strangers who I had never seen before knew me, watched me, and talked about me.

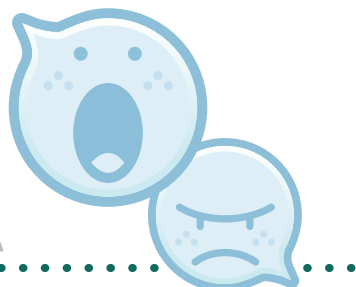
These hallucinations scared me so badly that I ended up taking a military pickup truck on a high-speed chase in order to escape the police, my many mind wars, and scary thoughts. My living nightmare got worse when I was jailed and hospitalized for five months. Fortunately, my diagnosis set me free. This newly found knowledge and treatment saved my life from the ongoing nightmare, which was my undiagnosed schizophrenia.

Between age 20 and 31, I participated in a clubhouse for young adults with mental illness ages 16 to 24. I stayed in the program for almost a year that provided therapy, housing, and recovery-oriented classes similar to Mary Ellen Copeland's WRAP. It also provided a safe haven for us to relate, and to socialize in a setting without stigma. Afterwards I became involved with NAMI Georgia, otherwise known as the National Alliance on Mental Illness. Through the years I created a strong support system including peers, family, and my treatment team. I engaged online, and created a blog, Overcoming Schizophrenia. I published *What's on My Mind* in 2014.

In 2018, I was hospitalized a second time. I was medication compliant, but a significant load of stress led to my last hospitalization. My diagnosis is now schizoaffective disorder. Fortunately, my support system stood strong and worked well for my recovery. With the aid of my support system, old coping skills, and hope to reunite with my son, I was in and out of the hospital and in a good place faster.

I would like to see others maintain a place of good mental health, as I have. Taking medication, working on managing stress, and developing a post-crisis plan have been vital in my recovery.

OVERCOMING SOCIAL STIGMA



A Project to Reduce Stigma about Schizophrenia through Middle School Education

by Cassidy Ehrman

If asked a year ago what I thought schizophrenia was, I would've said it was a disease that made people crazy. The stereotypes I had heard from social media and conversations in general had led me to inaccurate assumptions about this disease. However, through learning about schizophrenia under the mentorship of Dr. Carol North, I realized that the misconceptions I held about schizophrenia reflect a general misunderstanding throughout society. This misunderstanding is a basis of stigma that can impede the lives of victims in ways unimaginable to those that have not experienced it. Once I learned for myself the truth about schizophrenia by reading authoritative sources and listening to public presentations by respected professionals, I knew that I had to do whatever I could to change the perceptions of people in society about this unfortunate illness.

At this point in my journey, I had a goal but no clear means of attaining it. I had to start somewhere. I knew that I wouldn't be able to make as large of an impact as I would have liked to, but I kept my mind open to different possibilities. After much research, discussion, and thought, I decided to educate middle school students about schizophrenia.

After contacting the principal of one of the middle schools in my area, I scheduled a meeting with her and the health teacher that I would be working with. Both of them were very interested in my idea, and it fit in well with the mental health curriculum that the students would be learning when I went in to teach them. I was invited to make 45-minute presentations to 3 middle school health classes. I compiled all of my research into a format that would be suitable to teach and interesting to the students.

To me, the most beneficial aspect of this project was the collection of data about the students' beliefs both before and after my presentation. Before, I had them tell me what they already knew, or thought they knew, about schizophrenia. After, I asked them questions about what they learned and how their impressions of the disease changed because of what they learned during the presentation. In all of the classes the students told me that if they met someone with schizophrenia they would be more open minded and would also have a better idea of how to best communicate with them. Additionally, the students said that if they heard others spreading lies about schizophrenia they would be able to step in because they now knew the correct information.

Teaching middle school students about schizophrenia not only helped them learn, but also showed me how possible it is to reduce stigma within a community. While it did take time and effort, I was able to influence others with the hope that this progress will last and continue to grow. A year ago, I too had ill-informed prejudices against those with schizophrenia, but this was solely due to my lack of education on the matter. Through my experience, I was able to see first-hand the difference that education can make.



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TALK THERAPY

is Important in Schizophrenia

Recovery requires more than medications. You don't just treat psychiatric disorders with a pill.

It is important to have a deeply caring support team around you. Your work with members of your treatment team is a partnership. With time, a psychiatrist and members of one's treatment team should feel like coaches, mentors, or even friends.

Talk therapy can serve as social skills training and vocational rehabilitation. As individuals recover and rebuild their lives, it is important to celebrate milestones such as a graduation or landing a new job. Feeling comfort and reassurance is vital.

In other diseases like cancer, friends and family often send chocolate, cards and flowers, but in schizophrenia, people in your life may not know how to respond. Often times, friends and family members will avoid a person with schizophrenia. Because individuals with a psychiatric disorder tend to isolate themselves, social interaction is especially important. People with schizophrenia need companionship and human contact more than anyone else.

Family and friends must choose to not buy into the stigma, and to be compassionate. They should also be patient. Recovery takes time.

Persons with schizophrenia need to know that their doctors, families and treatment team want them to get better, and will do whatever it takes to bring them to their highest level of recovery.

VIDEO HIGHLIGHT



Please consider making a donation to the CureSZ Foundation online at CURESZ.org

Your contribution will help provide education and referrals to patients, their families, and those who work with the seriously mentally ill. CURESZ informs the general public to better understand this serious brain illness, and to provide scientific advances showing that there is hope for recovery, and a return to a fulfilling and normal life. The CURESZ Foundation is a 501(c)(3) nonprofit organization. All contributions are tax deductible.

"We are committed to helping patients to cope with and recover from schizophrenia."