

Courage, Compassion and Resilience

One of the challenges of caregiving for someone living with a severe brain illness is contending with misunderstandings related to mental illness and struggling with the associated stigma. When our younger daughter's severe brain illness presented during adolescence, several people urgently offered advice. While most of the information and recommendations were well intentioned, some were rooted in fear, disbelief, and a fundamental misunderstanding of her severe brain illness. Some comments took the form of opinions about her condition and its causes, essentially assigning blame. This sort of advice briefly threatened to undermine our daughter's medical and therapeutic care, by suggesting that she should be able to address her symptoms without the need for professional care and medication.



Gayle Ayres

"Caregivers must stand firm in the midst of emotional anxiety, uncertainty, and assumptive blame."

With the goal of enhancing our younger daughter's treatment, I began meeting privately with our family's cognitive behavioral therapist. She made a profound difference by helping us understand her severe brain illness and chart a caregiving course, and by emphasizing the need to establish boundaries and practice self-care. I encourage every caregiver to meet with a therapist as they take on their new role.

I also sought spiritual counsel from a pastor I greatly respect, and he encouraged me to study leadership. As a first step, he recommended the book, *A Failure of Nerve: Leadership in the Age of the Quick Fix*, by Edwin H. Friedman. This book has been a substantial and positive influence, and has complemented my own experience with cognitive behavioral therapy.

Following a model of what Friedman refers to as "self-differentiated leadership," we caregivers must be willing to stand firm – at the risk of displeasing others – in the midst of emotional anxiety, uncertainty, and assumptive blame. We must allow ourselves to be vulnerable, but not succumb to fear, criticism, or worry. We must set boundaries with people who intentionally or unintentionally sabotage the care of our loved one, especially if his or her symptoms are sabotaging needed medical and therapeutic care. And we must separate ourselves from drama and gossip, yet continue to remain connected and focused on recovering together as individuals, families, and communities. We do not insist that everyone follow; rather, we encourage them to participate in the recovery process.

Bear in mind that this initial stage in brain health recovery will most likely involve the pain of isolation. But when we show up, when we are willing to learn, change, and grow, when we decide to patiently, lovingly, and kindly serve through caregiving, we have the potential to transform our loved ones' and our families' recoveries well beyond anxiety and apprehension by caregiving with self-differentiated leadership skills. We realize recovery is taking place when we see those involved with the process, especially those in our care, take on the role of a self-differentiated leader. As caregivers, there is no greater joy than seeing those in our care exercise responsibility for their care, and become leaders with a strong sense of self and purpose.

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SCHIZOPHRENIA SURVIVORS



The Story of Rebecca Chamaa



CureSZ **Brain Facts**

Preventing the Nongenetic (Environmental) Risk Factors for Schizophrenia

by Henry A. Nasrallah, MD
CureSZ Scientific Director

Schizophrenia is a neurodevelopmental disorder. In a previous issue, I summarized the genetic factors that disrupt brain development during fetal life, leading to schizophrenia in adulthood. The following are environmental risk factors during pregnancy that can alter brain development and lead to schizophrenia in early adulthood: Infections, severe vitamin D deficiency, diabetes, severe stress (like death of the spouse), smoking, high BMI during the first trimester, hypothyroidism, starvation, and delivery complications.

Thus, good prenatal care is vital to lower the risk of schizophrenia in the offspring of a pregnant woman. This includes: immunization, vitamin D supplementation, managing diabetes before and during pregnancy, balanced diet, avoiding smoking or drug abuse, avoiding exposure to cat litter which contains toxoplasma gondii (30 studies show it to increase risk of schizophrenia), uneventful delivery without hypoxia to the fetus.

Finally, old paternal age at the time of conception (> 45 years) has been reported to triple the risk of schizophrenia due to higher rates of sperm DNA fragmentation, so men should preferably have babies in their 20s and 30s to minimize that risk.



Rebecca Chamaa, author

In my late twenties, I began to struggle with paranoia. I believed that my food was poisoned, and that people in my life were conspiring against me. Eventually, my mother and aunt convinced me to willfully enter a psychiatric facility. My diagnosis was bipolar disorder with psychotic features.

At first, it was difficult to accept my diagnosis, and I wasn't committed to treatment. However, once I took my treatment seriously, I remained healthy and stable. I was thriving for seven years. From 1999-2006, I worked as a library technician and a marketing coordinator. In 1998, I married my friend from high school.

In 2005, my psychiatrist of six years determined I was not mentally ill and took me off all medications. A year later, I became acutely psychotic. By this time, I was in a new city and was assigned a new doctor. My next doctor changed my diagnosis to schizoaffective disorder. It was later changed again to paranoid schizophrenia.

I know that my diagnosis sounds intimidating to some, maybe a little bit frightening, and is a mouthful, but please try not to fall back on myths or stereotypes when you apply those words to me or anyone else. I have come a long way since that diagnosis of bipolar disorder, and I have lived a full and rewarding life. I would not suggest it has been easy or has lacked difficulties, but each time the illness tried to crush me, I have rebuilt my life.

Like many other people with schizophrenia, I am a college graduate. From 2006-2011, I worked as a social worker. I am an avid writer and have recently published works in *Teen Vogue*, *Ravishly*, *The Fix*, *The Mighty*, *Good Housekeeping* and *Women's Day*.

I am currently embarking on a writing career, and I have published two books. One is a short prose and poetry book called *Pills, Poetry Prose: Life with Schizophrenia*. The second one was released this September and is called *A Guided Mental Illness Journal and Workbook*. This second book is a self-help book for people struggling with self-confidence or coping skills. It has sixty days of exercises, writing prompts and tasks designed to help individuals get past the symptoms of mental illness. They are both available on Amazon.

This year, in 2018, my husband and I celebrate twenty years of marriage. If you met me, you might note that I have a very distinct and loud laugh, a big smile, and I love to talk to people at grocery stores, coffee shops, bookstores, and wherever else I find a captive audience. Of course, I am simply trying to point out that my diagnosis isn't what defines me. **On most days, in most places, my illness would go unnoticed, and that is exactly how I want it to be.**

OVERCOMING SOCIAL STIGMA



Stigma and Trivialization of Mental Illness in Social Media

by Sai Movva, student at Heritage High School in Frisco, TX

A new article¹ about stigmatization and trivialization in social media, published online August 1 in a psychiatric journal, caught my interest. The study described in this article examined mental health stigma in social media in 1,300 tweets about schizophrenia randomly sampled from a total of 1,059,258 tweets referring to five medical and five mental disorders. The study found that stigma and trivialization were found more often in tweets about mental disorders than about medical disorders. According to the study, in social media, schizophrenia was the most stigmatized (41%) of the mental disorders in tweets, far more than physical disorders (8%). The most trivialized disorder was obsessive compulsive disorder (33%), far more than physical disorders (7%).

Stigma within these tweets was expressed in the form of demeaning jokes, negative stereotypes, wishing illness upon someone, and associating illness with undesirable attributes, often as part of an insult. Trivialization was expressed as minimizing the illness or its suffering or difficulty recovering from it and glamorizing illness. Both stigmatization and trivialization of illness can cause people with psychiatric illness to suffer in silence, feel ashamed of their problems, and avoid seeking help.

There have been numerous campaigns aimed at reducing stigma against mental illness, yet stigma persists. Findings from this study suggest that anti-stigma campaigns need to extend efforts online and in social media to help people understand mental illness and specifically avoid using – and discourage others from using – language that is stigmatizing or trivializing toward mental illness. Specifically, education programs can help people comprehend the harm created by using the word “psychotic” as an insult or by invoking mental illness to disparage or ridicule others. The increasing use of social media throughout all levels of society and the widespread stigma propagated by it imply that anti-stigma programs will need to target diverse demographics and expend efforts across the constantly evolving forms of communication to change prevailing views about mental illness. Only through such efforts can we hope to eradicate the pervasive stigma that amplifies suffering and isolates people with mental illness from needed sources of social support and professional care.



Sai Movva writes under the guidance of Dr. Carol North, MD.

Dr. Carol North (photo above) serves as Medical Director of the Altshuler Center for Education & Research at Metrocare Services in Dallas, Texas. She holds The Nancy and Ray L. Hunt Chair in Crisis Psychiatry and is Professor in the Department of Psychiatry at The University of Texas Southwestern Medical Center in Dallas, Texas.

Reference: 1. Robinson P, Turk D, Jilka S, Cella M. Measuring attitudes towards mental health using social media: investigating stigma and trivialization. Published online August 1, 2018 in *Social Psychiatry and Psychiatric Epidemiology* (doi: 10.1007/s00127-018-1571-5).



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TARDIVE DYSKINESIA

EXPERT PANEL

The CURESZ Foundation has assembled a Tardive Dyskinesia (TD) Expert Panel of psychiatrists, neurologists and nurse practitioners throughout the United States, who have extensive experience in the diagnosis and pharmacological treatment of tardive dyskinesia.

For decades, TD has been untreatable. However, in 2017, two new medications for TD were approved by the FDA, valbenazine and deutetrabenazine.

The CURESZ Foundation will refer patients with TD to the clinicians on the CURESZ TD Expert Panel for assessment and treatment. Panel members will be available to evaluate new patients who have TD, and/or to correspond with their doctor to coordinate care as needed.

There is significant need for more physicians with expertise in recognizing and treating TD. In the U.S., 2.5 million schizophrenia patients and over three millions individuals with bipolar disorder receive dopamine receptor blocking agents and are at risk for developing TD. Additionally, there are over ten million individuals with depression, many of whom are prescribed FDA-approved adjunctive atypical antipsychotics because they respond only partially

to their antidepressant medication. Thus, hundreds of thousands of people nationally are at risk for developing TD.

Dr. Henry A. Nasrallah, CURESZ Vice-President and Scientific Director, who spent many years conducting research into TD and publishing articles about this serious iatrogenic movement disorder, will serve as chairman of the TD Expert Panel.

We welcome additional applications to our TD Expert Panel at:
curesz.org/tardive-dyskinesia-panel/

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 and their families, 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."