CureSZ
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CURESZ FOUNDATION
Newsletter
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Comprehensive Understanding via Research and Education into SchiZophrenia

The Three Stigmas of Schizophrenia

In 2008, when fully recovered from schizophrenia, I was ready to disclose to family, friends and acquaintances about the particulars of my journey through schizophrenia into full and sustained recovery. It was important to me to explain all I had gone through and share that recovery from schizophrenia is indeed possible, thanks to antipsychotic medication. In my case, what brought me into high level sustained recovery and a new life was the only FDA-approved medication for treatment-resistant psychosis.

However, when sharing my journey with new friends at the university, as well as old friends from various periods of my life, I generally received a negative response. People who heard my diagnosis distanced themselves and seemed to act as though I must be dangerous, or erratic, or perhaps no longer trustworthy.

It is my impression that the stigma of brain disorders in general, such as anxiety, bipolar disorder and depression, is improving. When celebrities such as Michael Phelps come out publicly with their stories of recovery, they normalize mental illness and provide insight. Today, bipolar disorder is often associated with creativity, productivity, and artistry. However, I rarely hear anything positive in the media about schizophrenia.

Bethany Yeiser, *President of the CURESZ Foundation*

For every story in the media of schizophrenia recovery (and yes, there are some[1,2,3,4]) there seems to be many others about violence and erratic behavior resulting from psychosis. Notably, these instances of dangerous behavior are generally associated with lack of treatment or noncompliance. Statistics confirm that people in treatment for schizophrenia are no more violent than the general community, yet many in the general public are unaware of this.[5]

In 2008, after disclosing my diagnosis and receiving a negative response, I refrained from disclosing to most people. However, this left me feeling alone, like I was living under a shadow. I felt isolated and reluctant to pursue deep and meaningful relationships.

In 2011, following my college graduation, my doctor encouraged me to write my memoir. I published *Mind Estranged* in 2014, disclosing everything.

Often, I am asked by other people with schizophrenia whether or not they should disclose their illness. I have no single answer for this question, as it is a personal choice. For me, it has been best to connect with others through common interests such as professional aspirations and hobbies, and build trust first. Once a relationship of trust and friendship is established, it is more natural to share medical issues. Certainly, having schizophrenia should not have to be the most important thing about a person's life.

One of my mentors over the years has been a successful Texas psychiatrist who recovered from schizophrenia and has practiced for decades. She once told me that the people in her life who knew her when she was sick cannot imagine her well. At the same time, the people in her life who know her today, healthy and thriving, cannot imagine her sick. I have found the same to be true in my own life. When I develop strong relationships with others today, I think it is hard for them to imagine me overcome by the devastating symptoms of schizophrenia.

In my experience, I have encountered stigma of schizophrenia at THREE LEVELS.

First, **In The General Public,** there is a strong tendency to negatively sensationalize and distort schizophrenia. On Halloween in the past, I have found *"Gone Mental"* holiday costumes in various stores. Some of my friends who advocate for people affected by brain disorders faithfully create petitions to either rename these costumes or get them out of stores. It always amazes me, as you would never see a diabetes costume, or a cancer costume. Yet mental illness is associated with fear, lack of understanding and sensationalism, which is cruel. Stigma in the general public can also lead to a personal stigma experienced in the lives of patients who have the diagnosis.

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WhatSZ IN THIS EDITION

WHAT IS 988?

and How Will It Help People with Psychiatric Conditions?

As of July 16, 2022, all telephone service and text providers in the United States were required to activate 988.

> *The 988 hotline connects families with mental health professionals who are available at all hours and every day of the year.*

Similar to 911, this 988 hotline was created in an effort to addresses mental health emergencies all around the country, including the five major U.S. territories. 988 also links directly to a veteran's crisis line.[1]

According to Dr. Margaret Balfour, *"It's estimated that [with] the 911 system nationwide, probably, about 40 million calls a year going to 911 have a mental health crisis that's involved that could be handled potentially by 988. That's a huge number of calls that could be diverted away from the police response system to a health first response where you're getting trained clinicians on the phone."*[2]

Because 988 will put the family or person in crisis directly in touch with suicide prevention and mental health crisis counselors, it is hoped that most of the crises will be resolved over the phone. SAMHSA said, *"while some safety and health issues may warrant a response from law enforcement and/or Emergency Medical Services (namely when a suicide attempt is in progress), the 988 coordinated response is intended to promote stabilization and care in the least restrictive manner."*[3]

Police officers will only be dispatched to your house or other location in rare cases.

The *"988 suicide and crisis hotline"* is supported by the Substance Abuse and Mental Health Services Administration (SAMHSA).

I remember a time fifteen years ago when 988 did not exist, and my parents called 911 to deal with my mental health emergency. I had gone off my medication and was acutely psychotic. Fortunately, I was not handcuffed or treated roughly by police, who respected my dignity and calmed me down, trying to make light conversation with me, which I appreciated. The crisis resolved with a hospitalization that was a turning point in my life. Since that time I have always stayed on my medication and have achieved full recovery which allows me to live a fulfilling, healthy life.

In many other cases, patients may not be so fortunate, and the outcome can be negative.

I recently interacted with a family whose son appeared to be suffering from mental health problems. He was friendly, smart, and enjoyed fixing things. In the 1990s after the launch of the world wide web, he taught himself how to create a personal website. He took his computer apart and put it back together. Additionally, he independently learned a computer language, Linux.

But what he really loved most was roller blading, skateboarding and snow skiing. He loved spending time with many friends. His life was full, and he looked forward to a bright future.

His family never dreamed that one day, he would become severely mentally ill, and would cut off all connections with old friends and family members and lose a job where he had been very financially successful, as well as very happy. In times of good health, he enjoyed the sport of hunting and collected guns, which he kept with him long into his illness.

Eventually, due to many significant and troubling changes in his life, his father called the police requesting a mental health evaluation. He believed his son was mentally ill and wanted to make law enforcement aware of his gun collection. Unfortunately, this father was largely ignored. The young man had not yet been diagnosed with a mental illness. He was not yet considered a *"danger to self or others"* so could not be forcibly committed to a mental health facility for evaluation.

A few months later, in the middle of a mental health crisis, neighbors called 911. The young man was shot by police that day and died instantly.

The story of this young man is unique, and yet, it is only one of an increasing number of tragic mental health events throughout the country and the world.

It is my sincere hope that 988 will save the lives of many Americans struggling with mental health crises and help mentally ill persons look forward to the brighter future – a future that many can only achieve when consenting to life-saving treatment during a time of crisis.

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CURESZ
RESOURCES

At least 8.4 million people in the U.S. provide care to an adult with a mental or emotional health issue. Caregivers of adults with mental or emotional health issues spend an average of 32 hours per week providing care.

Families who have a loved one with schizophrenia often find themselves frantically searching the Internet for resources that will improve the situation of the one they care for. Sometimes, caregivers can become exhausted and can feel depleted of options and of hope.

CURESZ FRIENDSZ

This caregiver mentoring program partners individuals with extensive experience caring for a loved one with schizophrenia with newer caregivers *(mentees)* who may have less experience, or who are seeking support at any stage of their caregiving journey. Mentors offer support and encouragement by *"walking"* alongside the mentee, offering their own personal experiences. They do not provide medical or legal advice, and they are not licensed counselors, but they are loyal and dependable friends. Enduring friendships have been forged through this program. Our goal is to ease the burden of caregiving through compassionate one on one support.

To date, the CURESZ Foundation has paired over 90 mentees with mentors. **CURESZ Friendsz** is directed by CURESZ Board Member Catherine Engle, LPCC-S.

> "I wanted to send you a huge THANK YOU. You connected me with a mentor [named] Georgia. I wanted you to know that this has been one of the most positive experiences. As I have navigated through my son's recent episode, three hospitalizations, and medication change Georgia has been there like a rock for me to lean on. She helped me find hope and new perspective when I felt at my lowest point. Thank you for setting up this program and connecting us. I am forever grateful."

In addition to the **Friendsz** program, the CURESZ Foundation provides many other important resources.

CURESZ.ORG & CURESZ YOUTUBE CHANNEL

These websites offer extensive educational and clinical information about schizophrenia, comorbidities and related disorders. This includes our *Clozapine in Schizophrenia Expert Panel* webpage where families looking for a doctor who prescribes clozapine, or find a physician for a second opinion or possibly ongoing care. The website also offers an extensive archive with Newsletters focusing on many topics.

CURESZ ON CAMPUS CLUBS

The typical onset of schizophrenia commonly occurs between the ages of 18-25 years old. Unfortunately, this time frame coincides with college years when so much is already at play in a young person's life. **CURESZ Clubs** educate students about brain disorders including schizophrenia, bipolar disorder, anxiety and depression, warning signs and treatment options. CURESZ sponsors campus clubs at the **University of Cincinnati** and **Babson College** in Boston. We also have members who attend our virtual events from all around the country. During the school year, we usually hold one in-person event per month plus one virtual event per month. Most club members are undergraduate students studying nursing, counseling, or planning to become a doctor or researcher, as well as students from all majors who have an interest in mental health. Many members have siblings or family members struggling with brain disorders. We are actively searching for new club student leaders.

MONTHLY SUPPORT GROUP

Families faced with the challenges of a loved one's illness can find encouragement and support from families whose loved one has achieved recovery. Visit the contact form on CURESZ.org to register.

ASK THE DOCTOR

Monthly events where six families have 90 minutes to ask a CURESZ psychiatrist anything about brain disorders. Although this is not a forum where individual cases are discussed, it is a valuable opportunity to receive expert medical information.

FINDING A MENTOR THROUGH CURESZ

If you are interested in becoming a mentor or mentee through **Friendsz**, we ask you to complete a questionnaire with your contact information, age of your loved one with schizophrenia, age of onset, religious preference, and other information.

Whenever possible, we like to pair mentees with mentors based on geographic location and/or based on situation when possible. For example, the mentee's loved one may be struggling with treatment noncompliance or substance abuse, lack of insight, or may be actively psychotic. In each of these situations, a specific mentor's experience may be invaluable to the mentee.

We are also always looking for new mentors. If you want to become a mentor, we ask for a 15-minute interview over zoom, a background check, and that you view an hour-long training video.

We hope you will share **CURESZ Friendsz** with those you know who have loved ones with schizophrenia, as well as any caregivers in your support groups or community.

To learn more about **CURESZ Friendsz** or to browse the many educational resources we offer, please visit CURESZ.org today.

Catherine Engle, *LPCC-S*
CURESZ Board Member and Director of CURESZFriends

"I have been working in the mental health field for the past 12 years and completed my master's degree at Xavier University in clinical mental health counseling. During my undergraduate studies, I had an encounter that became the catalyst for my career in the mental health field. I met a woman who expressed that her son had recently been diagnosed with schizophrenia. She was a single mother and said she felt completely overwhelmed and unsure of how to help him or get the support for herself that she greatly needed. The CURESZ Foundation impressed me so much as I learned more about it. To me, it's about offering others information, empathetic connection, and support so they can feel empowered and navigate a successful future and the best quality of life for themselves and the loved ones they are caring for."

The Three Stigmas of Schizophrenia

(continued from Page 1)

I have experienced schizophrenia stigma **In The General Medical Community.** After recovering from schizophrenia, I contacted an old friend from my undergraduate years. While she had spent four years in medical school, I had not yet finished my undergraduate degree and additionally had spent four years homeless. After she made an effort to find me over social media, I was excited to describe how well I was doing in my full recovery from schizophrenia. I did not expect her response of fear and lack of understanding. After a single phone call where I disclosed, I never heard from her again.

In 2008 prior to my recovery, I saw a family doctor for a routine checkup. When she saw antipsychotic medication in my chart, she told me *"You would not need this medication if you hadn't used drugs!"* I told her I had never used drugs. Her comment was judgmental and inappropriate, as many use substance to self-medicate, and substance abuse is in fact known to be a disability.

I have also experienced stigma **Among Psychiatrists.** When I was diagnosed in 2007, I was told after about 36 hours in the hospital that I was *"permanently and totally disabled."* The doctor did not offer hope for recovery. It seemed that leaving the hospital and being stable enough to even live in the community was the highest goal I could hope for. Unfortunately, subsequent psychiatrists also offered little hope and limited options to recover and rebuild my life.

Fortunately, in 2008, I met Dr. Henry Nasrallah whose thinking was quite the opposite. Dr. Nasrallah researched my life, including my research publications, violin accomplishments, and high grades prior to the onset of my schizophrenia. Subsisting in the community was not good enough for him — he was determined to do anything in his power to get me back to college, back to work and back to meaningful relationships. I owe a debt of gratitude to him for his dedicated care and forward thinking. He helped me achieve full recovery with clozapine and social support, allowing me to finish my college education and publish a book about my journey of recovery, and then serve as president of the CURESZ Foundation, which we established together in 2016.

When it comes to stigma of schizophrenia, I feel we have a long way to go. However, stories of full recovery (which I hope include my own) prove that today recovery is truly possible.

I am honored to have the opportunity to speak and write about my recovery with hopes that this stigma will greatly diminish over time. As I encounter so many others in full recovery, I am optimistic.

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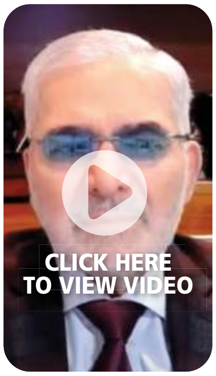
VIDEO HIGHLIGHT



The Need for a New Name for Schizophrenia

by Dr. Henry A. Nasrallah

The name schizophrenia, coined a century ago, is loaded with stigma from the era of insanity and hopelessness. Today, schizophrenia is considered part of the *"psychosis spectrum disorders."* Three Asian countries have already adopted a different term.

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

Your contribution will help provide education and referrals to persons with schizophrenia, their families, and those who work with the seriously mentally ill. CURESZ informs the general public to better understand this serious brain disorder, 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 individuals to cope with and recover from schizophrenia."

You can now also support the CURESZ Foundation by signing up with Kroger Community Rewards and Amazon Smile.

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