CURESZ FOUNDATION
Newsletter
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*Comprehensive **U**nderstanding via **R**esearch and **E**ducation into **S**chi**Z**ophrenia*

Living as a Therapist with Schizophrenia

Blending Personal and Professional Experience to Support Clients

One of the common misconceptions about mental illness is that it's invisible, only detectable when it reaches a breaking point. As someone who lives with schizophrenia and works as a therapist, I can confidently say this isn't true. Mental health changes, both positive and negative, often reveal themselves in subtle but telling ways – through shifts in eye movements, gait, or slight cues in speech patterns. Through therapeutic observation, understanding symptom intensity, frequency, and progression in clients becomes more nuanced, especially because of my lived experience with my own symptoms.

Recognizing Patterns through Shared Experience

Living with schizophrenia has taught me to recognize the rhythms of symptom progression and the nuanced signs of decline. When a client begins to slip – becoming more symptomatic or showing signs of worsening – there's often a pattern. Perhaps their speech becomes more disjointed, thoughts more fragmented, or movements less deliberate. Because I know these signs in myself, I can detect similar shifts in my clients with heightened sensitivity.

This shared experience not only makes me more attuned to subtle changes in clients but also deepens empathy and understanding. I know firsthand the challenges that come with becoming more symptomatic, and this insight allows me to connect more meaningfully, helping clients feel supported and validated.

Max Guttman

Observation as a Tool for Therapeutic Insight

Observation is a powerful tool in therapy. By carefully monitoring behavior, language, and physical cues, I gain insight into a client's mental state. Changes in eye movements, pacing, or posture can be early indicators of a shift in mood or stability. These physical indicators are not just symptoms of a disorder; they're clues to a client's current capacity to cope and their level of resilience.

When combined with knowledge of a client's history and baseline, therapeutic observation becomes even more effective. By establishing each client's "norm" through regular sessions, I can spot shifts and adapt our approach as needed to address emerging challenges or reinforce strengths.

Resilience in Recovery and Symptom Management

Mental illness affects everyone differently, and resilience plays a central role in how symptoms are managed over time. Resilience is a skill that can be cultivated, a foundation allowing individuals to face challenges with stability and strength. As a therapist, part of my role is assessing this resilience in clients and understanding how it impacts their ability to cope with stressors.

Resilience often becomes visible in how a client responds to setbacks, processes feedback or adapts to change. Even when symptoms are present, those with stronger resilience tend to recover more quickly and maintain stability. Nurturing resilience in clients involves offering tools to recognize and respond to symptoms before they become overwhelming.

Turning Lived Experience into Therapeutic Strength

As someone living with schizophrenia, my understanding of symptoms and progression isn't just theoretical – it's deeply personal. I recognize the signals of decline because I've had to monitor them in myself, learning when to seek support or focus more on self-care. This self-awareness has become one of my most valuable tools as a therapist, helping me empathize with clients while also guiding them with practical, lived insights.

Working with clients who experience mental illness allows me to translate my experiences into therapeutic practice. I help them understand their own patterns and empower them to seek support when necessary. Together, we develop strategies for managing symptoms and maintaining stability.

continues on page 4

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WhatSZ IN THIS EDITION

Schizophrenia Survivors – Neesa Sunar Pg 2

The Elusive Diagnosis of Tardive Dyskinesia in Psychiatric Practice Pg 3

Living as a Therapist with Schizophrenia: Blending Personal and Professional Experience to Support Clients *(cont. from pg 1)* Pg 4

CureSZ News

SCHIZOPHRENIA SURVIVORS

Neesa Sunar

Neesa experienced a difficult childhood. Living with a volatile and abusive father triggered depression at a young age. From age five, she felt angry and depressed, and remembers how home felt like "jail." She was also bullied at school for being tall and of mixed-race heritage. Deep-set feelings of hatred would follow her into adulthood.

Fortunately, in first grade, Neesa found a passion she still cherishes today – music. She was privileged to begin violin lessons at an excellent Suzuki school in her neighborhood.

But at age 11, Neesa spiraled into severe depression, and experienced suicidal thoughts by age 12. At this time, she switched to playing viola, and her mother also placed her in private school, hoping she would fit in and have more success. Things did not improve fully. At age 14, she was hospitalized for depression and prescribed Zoloft and Klonopin. She began therapy, which she would continue throughout her life.

At age 15, Neesa began studying music with a violist from the New York Philharmonic. Excelling in music, she found her identity and confidence. She scored A's in high school and participated in competitive youth orchestras in the NYC area.

For college, Neesa accepted a full scholarship to study viola at Indiana University. At first, Neesa thrived on competition, but socializing was too stressful. Neesa had insight into her mental health struggles and adhered to psychiatric treatment on campus. At that time, she took the medication venlafaxine for depression.

At the end of her junior year, Neesa became involved with an East Indian meditation group. She meditated too intensely, and began experiencing grandiose spiritual thoughts. She lost focus on her musical studies, and her performance declined. She became obsessed with a "shooting energy" throughout her body, which she later understood to be Kundalini Syndrome. Her psychiatrist approved for her to stop taking venlafaxine, and this triggered severe withdrawal.

As a senior at IU, Neesa felt mentally unwell, but she still graduated with a 3.78 GPA and successfully auditioned for a master's program at IU, which she began in 2007. But her behavior was volatile and she was paranoid about classmates. For winter break, back in NYC, Neesa remembers visiting a pizza shop where she started crying uncontrollably, due to overwhelming spiritual thoughts. A worker called the police, and she was taken to a hospital where she would stay for three weeks, and was started on olanzapine. At that time, her diagnosis was changed from depression to schizoaffective disorder. Fortunately, Neesa had good insight into her illness and never refused medication or treatment.

Neesa never completed her masters degree at IU.

Back in New York, summer of 2008, Neesa first worked as a hostess at a local deli. But due to constantly missing work, she was soon fired from her job.

Then she started teaching violin lessons at a local store. This inspired her to return to school at Queens College in New York to pursue licensure as a public school music teacher. At this time, she simultaneously taught 10 private students weekly, and worked a stressful job at a private school.

Neesa began to take Abilify, which caused her to gain 90 pounds. Despite taking medication as prescribed, she began having delusions that she was the reincarnation of Beethoven. When sharing this with others, most thought she was joking. She broke down in front of her boss, who drove her to the mental hospital where she stayed for two weeks.

At this time, in 2011, Neesa chose to stop working and go on social security disability. She found she hated living with her mother and wanted independence. She moved into a homeless shelter for two weeks, before she returned home. In 2012, Neesa was hospitalized for her eighth time. She was started on clozapine while continuing to take venlafaxine, and at this time, she chose to stop all musical work.

As Neesa began to recover, she found purpose through being trained and working as a peer support specialist. For six years, on clozapine, her symptoms were in remission, though she struggled with severe sedation and often felt physically sick. Her doctors always discouraged her from working full-time, and they told her graduate school would be impossible. But in 2017, she began to study social work at Hunter College in NYC, and graduated with an MSW degree in 2020.

Following graduation, Neesa still struggled. In 2020, due to side effects, she decided to stop clozapine, which quickly led to another hospitalization where clozapine was restarted. Fortunately, doctors lowered her dosage, which reduced side effects and improved her physical health. In July 2021, she began working as a telehealth therapist under supervision.

In 2023, Neesa received grant writing assignments and was commissioned to ghostwrite a book, a manual for a social services provider. For the first time, she could travel, and she chose to visit Germany. She discovered she could get clozapine refills without bloodwork (as was mandatory in the U.S.). For 10 months, she remained in treatment while in Germany, Spain, Andorra and India. She was treated respectfully and had no problems accessing clozapine.

In 2025, Neesa applied for a PhD program at the University of Salford in the UK, and she was offered a full scholarship with the Leverhulme Trust Aural Diversity Doctoral Research Hub (LAURA). **Today, Neesa is celebrating two years at her highest level of recovery.**

Today, Neesa thrives on a low dose of clozapine. She is excited about her PhD research: investigating the lived experiences of musicians with auditory aphantasia / anauralia (inability to hear thoughts as actual sound). To ensure her health and continued success, she remains in treatment at an NHS clinic, alongside support from Doromind (a virtual provider in the U.S.).

Neesa welcomes anyone with interest in schizophrenia recovery to contact her at neesa.sunar@proton.me. She anticipates a brighter future, and envisions a world that better understands schizophrenia and the possibility for meaningful recovery.

The Elusive Diagnosis of Tardive Dyskinesia in Psychiatric Practice

Carol S. North, *MD, MPE, DLFAPA, Adjunct Professor in Psychiatry (volunteer), The University of Texas Southwestern Medical Center, Dallas, TX, USA*

Tardive Dyskinesia, or TD, is an involuntary movement disorder that can occur after treatment with antipsychotic medication. This condition can be hard to reverse and may cause embarrassment, stigma, social isolation, reduced quality of life, and problems with daily functioning. A published review of 41 studies of TD with 11,493 patients taking antipsychotic medications found that 25% developed TD.[1] TD differed across studies and groups of patients but was highest among state psychiatric hospital inpatients.

To examine TD in a real-world setting, we did a study at a large community mental health treatment center, Metrocare Services, in Dallas, Texas.[2] At the time, this facility provided outpatient care each year for serious mental illness and developmental disabilities to 62,000 adults and children. We reviewed medical records of more than 120,000 Metrocare outpatients treated from 2013 to 2017. Nearly one-fourth of the patients had a psychotic disorder, and one-fourth were children under 18. About 80% of both adults and children with psychotic disorders were prescribed antipsychotic medication.

A tool widely used to assess abnormal involuntary movements, including those associated with antipsychotic medication use, is the **Abnormal Involuntary Movement Scale (AIMS).**[3] This scale was built into Metrocare's medical record system, reminding providers to check for abnormal movements at least once a year. However, only about half (51%) of the patients receiving antipsychotic medication had AIMS information entered in their medical records. In the records that were completed for patients prescribed antipsychotic medication, only 1% of adults and almost no children were found to have TD, typically affecting the face, extremities, and trunk. Only one-third (32%) of the patients with a positive AIMS test had TD diagnosed by the provider. In summary, the public sector workers in our study did not always complete and record AIMS testing, and they rarely identified TD.

Our study used information recorded by busy providers as part of their normal outpatient care in a real-world setting. Another study also using medical record data found TD in only 1%-2% of patients.[4] The rates found in these clinical studies are substantially lower than the general 25% rates[1] reported by research studies dedicated to systematic recording of symptoms. The findings from these clinical studies suggest that clinicians may not be assessing for TD or are missing it when they do. This may be because they do not have enough time or staff to do regular formal movement checks.[3,5]

These findings matter for the many patients in public sector psychiatry and general psychiatric care settings with psychotic disorders who are prescribed antipsychotic medications.

> *"Because medications to treat TD are now readily available, it is more important than ever to identify and treat TD."*

This may be accomplished by training clinicians to systematically assess for TD, using better medical software to track abnormal movements, and giving clinicians enough time and staff for identification and treatment of TD.

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VIDEO HIGHLIGHT

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WHAT ARE THE SYMPTOMS OF

TARDIVE DYSKINESIA?

(Part 1 of 4)

Dr. Henry Nasrallah (Vice President of CURESZ) and Bethany Yeiser (President of CURESZ) talk about tardive dyskinesia, a common side effect of antipsychotic medications.

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This newsletter was supported by a grant from **Teva Pharmaceuticals**

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Living as a Therapist with Schizophrenia: Blending Personal and Professional Experience to Support Clients

(continued from page 1)

Therapy Beyond Medication

Schizophrenia is commonly thought of as a disorder managed primarily through medication. While medication is crucial in managing symptoms, it's only part of the story. Therapy, with its diverse approaches, is essential in supporting clients and myself. Cognitive Behavioral Therapy (CBT), psychoeducation, and Dialectical Behavioral Therapy (DBT) provide invaluable resources for understanding thought patterns and developing effective coping mechanisms.

For my clients, therapy contextualizes their experiences and validates the overwhelming reality of schizophrenia. For me, therapy has become a roadmap, helping me better understand my symptoms and navigate challenging times with a proactive approach.

Finding the Right Treatment Fit

A vital aspect of mental health care for schizophrenia is creating the right "treatment fit" – a combination of approaches tailored to each individual. This treatment might include medication, therapy, peer support, vocational training, and wellness practices. Each piece of this treatment puzzle contributes to a client's stability, just as it does for me.

My clients often present unique needs and challenges, and finding the right fit requires patience and experimentation. We may test various therapeutic modalities or explore wellness practices like mindfulness, structured routines, or social engagement – all of which play significant roles in managing schizophrenia.

Being a Prosumer: Both Provider and Recipient

Living with schizophrenia while working as a therapist positions me uniquely as a "prosumer" – someone who is both a provider and consumer of mental health services. This dual role enables me to help others from a place of empathy and lived experience. I understand the complexities of treatment and the courage it takes to trust a provider. Yet, as a therapist, I also value evidence-based practices and structured support.

Being a prosumer has been essential to my recovery and management of schizophrenia. This role empowers me to advocate for clients while continuing my personal journey toward wellness. Balancing treatment for others with self-care has allowed me to live with stability, free from frequent crises. The structure of my work, the relationships I build, and the insights I gain contribute to a solid foundation that sustains us both.

The Power of Purpose in Recovery

Purpose has been central to my recovery. I became a social worker not only to help others but to better understand myself. Purpose in recovery provides direction and motivation. My work keeps me engaged with new research, evolving treatments, and the voices of those who bravely navigate mental health challenges.

For those feeling discouraged by their diagnosis, I encourage you to consider the role of purpose, whether through advocacy, creativity, or routines. For me, purpose is rooted in helping others heal – a process that mirrors my own journey toward wellness.

Mental Illness is Visible – and Manageable

For those who observe closely, mental illness is far from invisible. By combining careful observation with empathy and guidance, I help clients recognize their own patterns, strengthening their capacity to cope and building resilience. With the right support, managing schizophrenia is achievable, and stability is sustainable.

Recovery is a journey, not a destination, requiring consistency, openness to change, and a willingness to try new approaches. I'm grateful to help others while continuing my path, and I hope that sharing this perspective brings encouragement to those navigating their own experiences with mental health.

We remember **MAX GUTTMAN** who passed away on April 19, 2025, at age 38. During Max's life, he wrote widely under the pen name J. Peters. Check out his feature on CURESZ.org and buy his book *University on Watch: Crisis in the Academy* through Amazon.

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."

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