

Schizophrenia and Support Groups

My perspective on schizophrenia support groups has changed over the years.

Throughout my life, I had always shied away from joining support groups. However, I now consider some of them to be indispensable.

I was diagnosed with schizophrenia in 2007. Upon my diagnosis, the doctor immediately and unswervingly determined me to be permanently and totally disabled. After a very difficult twelve months of failed medication trials, it began to seem his dire predictions were true – that I would never work, attend school or live independently. But in 2008, I proved every prediction he made to be wrong.

My expectations for support groups

The National Alliance on Mental Illness and other American organizations sponsor small chapters/support groups throughout the United States which can be found in most communities, even in rural areas. Shortly following my diagnosis, I became aware that a support group was available locally. However, I never really wanted to attend. I had no interest in meeting others who might be permanently and totally disabled like I was projected to be. I figured that anyone able to significantly recover enough from schizophrenia would quickly move on, and would naturally have no time for meetings while enjoying a new, healthy life, to the fullest.

I imagined a gathering where people confided the worst, nightmarish details, holding nothing back. I expected grief and tears as families and individuals with schizophrenia were trying to make peace with their disability, and no longer strive to higher levels of health and well-being.

Simply put, I had no desire to rebuild my life exclusively with people who shared my



Bethany Yeiser, President of the CURESZ Foundation

diagnosis. I wanted to have acquaintances and friends who were well, working, attending school and/or managing a family. Even during my twelve months of disability, I always clung to my belief that I could reestablish a life with acceptance by a diverse segment of society.

Hearing from others

Over the years, I have heard mixed reviews from others about support groups around the country. Some people who attend find what I hoped to avoid – a gathering of people making peace with permanent and unrelenting suffering with little hope. However, the more I questioned people and listened to their

stories, I recognized my impression may have been inaccurate. I heard reviews that were quite the opposite, including a fine review from a friend living with schizophrenia in Florida. For him, the support group both he and his family members found through their local NAMI became the building blocks of his new life. Today, he is fully recovered, has worked for several years, and is attending graduate school. He stays involved in the organization that sponsored his support group.

What I was more surprised to hear was about the diverse nature of these support groups. Different people have different personalities, and each support group takes on a personality of its own to meet unique needs. Some persons who attend groups have no family, while others are well supported. Sometimes, people in full recovery do attend and encourage those who are struggling. Persons who have been disabled for years may find both a new reason for hope through new treatment options and practical ways to make their lives fuller and healthier.

Finally giving it a try

Following my recovery from schizophrenia (thanks to clozapine, as I was treatment resistant) a local support group I had chosen never to attend invited both me and my mother to share our stories, including both my perspective on my illness and hers as both a mom and a nurse. Though the support group that evening was very small, it was rewarding to give back. And most importantly, to offer hope, rather than just acceptance of disability.

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SCHIZOPHRENIA SURVIVORS



Meghan J.M. Caughey



Meghan J.M. Caughey is currently a Clinical Assistant Professor at the Oregon Health and Science University, Department of Psychiatry. She works in the Public Psychiatry Training Program and a suicide prevention program.

"No one had ever thought I could work, but my career began at age fifty. I designed and directed mental health programs in Oregon. I finally ended up in Portland, Oregon, as Senior Director of Peer Wellness Services at a large health nonprofit."

Learn more about Meghan, her art and her book here:

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mudflowerbook.com
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I grew up in Atlanta, Georgia, feeling invincible as a little girl. I played violin and cello and was a page in the Georgia State Legislature, where I lobbied for civil rights and against the war in Viet Nam. I assumed I could do anything; I spent most of my time drawing and playing my cello in high school. I discovered Zen Buddhism and focused on meditation, art, and music.

I selected a university based on its proximity to the Rocky Mountains. I believed I needed the solitude in the wilderness. At Colorado State University, I studied art and focused on backpacking in the Rockies. One afternoon in an art history class, I heard intrusive, cruel voices that no one else could hear. When I struggled to return to my dormitory, the people I saw didn't look normal – their faces looked like enormous insects. Later I looked at myself in the mirror, and I was no longer human. I had turned into an awful beast. My world fell apart. Some other students saw how disturbed I was and took me to the student health center. I was given the medication Thorazine there and taken to see the psychiatrist. He pronounced, *"You have schizophrenia!"* Although I didn't know what schizophrenia was, it was clear that I was doomed.

In the following years, I was often hospitalized for my symptoms, which were visual, kinesthetic, and auditory hallucinations. I switched my major from art to psychology because I needed to understand what was happening to my brain. I was deeply discouraged and contemplating suicide, and I was able to do an independent study in Suicidology, getting college credit for obsessing about killing myself. My doctors would give me antipsychotic medication, but I hated the side effects, so I usually would stop taking it and then end up in the psychiatric hospital until I could be stabilized by retaking it. I went in and out of hospitals but eventually graduated with a bachelor's degree in psychology. Because being an art therapist would combine art and psychology, I went to an art therapy master's program in Vermont.

My symptoms became severe, but I tried to be an art therapy intern at the Vermont State Hospital. I was terrified to see a patient who had full-blown tardive dyskinesia caused by the same medication I was taking. I ended up in a psychiatric hospital and was tied down with four-point leather restraints.

I had to leave school and be treated in a residential psychiatric program. I detested psychiatric medication, so I ended up in a non-traditional program in Oakland, California, called the Cathexis Institute. They claimed they could cure schizophrenia without using medications. They said that schizophrenia was caused by faulty parenting and the cure was in *"reparenting"* patients. For my mother this was really difficult because she heard the term,

"Schizophrenogenic Mother" and she thought she was to blame for my mental problems. I wasn't allowed to have any contact with my family for over four years. They put adult patients in diapers in the therapists' laps and regressed adults to babyhood, including diaper changes. They practiced corporal punishment if a patient broke a rule.

I stayed in this program because I didn't have to take medication, but eventually, I ran away. I lived in a cabin in the Santa Cruz coastal mountains and intensely focused on my art. I went in and out of psychiatric hospitals, detesting the side effects of schizophrenia medications. I was determined to go to art school and completed a Master of Arts and then a Master of Fine Art in Pictorial Art despite the frequent psychiatric hospitalizations.

Eventually, I got married, but in the first year of our marriage, I made a significant suicide attempt – being married could not ease my emotional pain. After seven years, we were divorced. Then followed years of many hospitalizations and suicide attempts. I have been hospitalized well over one hundred times, sometimes in the Intensive Care Unit.

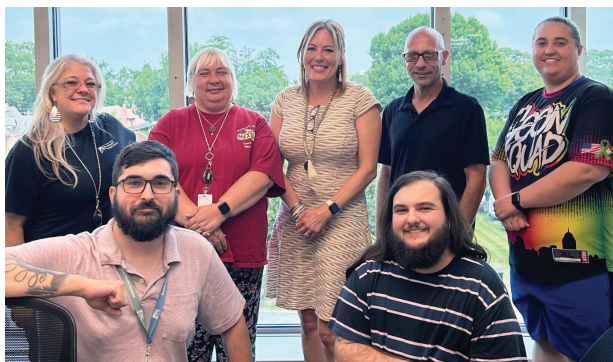
I attended a day treatment program. I learned about a medication called Ziprasidone in Phase III trials. I was forty-eight, and no one thought I would go beyond the psychiatric hospitals. However, I made the 18-hour trip from home to the California hospital every month for two years. I didn't have side effects, and my psychotic symptoms disappeared. I started to experience a new feeling – pleasure, which I had not felt in years. I stopped going to the hospital. The drug company trained me in public speaking, and I gave presentations at national medical conferences and advocacy events. Eventually, I pursued a career in activism in mental health and specialized in designing and directing peer-delivered services.

In 2021 I had Neuroleptic Malignant Syndrome (NMS) caused by the antipsychotic medication that had saved my life. I can no longer take this medication and sometimes rely on maintenance ECT to help address the lingering symptoms. I am a survivor.

I continue to make art, play the cello, and write. My memoir, *"Mud Flower, Surviving Schizophrenia and Suicide Through Art,"* 2021, has won twelve book awards. I'm now working on the sequel: *"Winged Beings: Making Art from the Lap of the Universe"* (See page 4).

Is it possible to heal from schizophrenia? I honestly must say that sometimes things can still be challenging, but it is possible.

It may not always be easy, but it is worth claiming freedom!



Greater Cincinnati Behavioral Health Services (GCBHS) has multiple programs that serve people who are experiencing severe psychiatric disorders such as schizophrenia and schizoaffective disorder, as well as programs that engage people who are struggling with homelessness. One of the programs that combines both the severe psychiatric disorders along with housing instability is our Homeless ACT team.

ACT stands for "Assertive Community Treatment" and is regarded as a high level, intensive care management team. In all, GCBHS has six ACT teams including Traditional ACT, an Integrated Dual Disorder Team (IDDT) for clients with a co-occurring mental health and a substance use disorder (SUD) diagnosis, a Forensic ACT (FACT) team that focuses on recently paroled individuals, two mental health court teams (Municipal and Felony), and the Homeless ACT team.

To qualify for a Hamilton County ACT team clients must be 18 years of age or older, live in Hamilton County and have a psychotic disorder such as schizophrenia, schizoaffective disorder, or a major depressive disorder with psychotic features. They must also have a Daily Living Activity score (DLA) under 30. The DLA score focuses on 20 different areas of life including housing, productivity, communication, safety, problem solving, and hygiene.

The Homeless ACT team is made up of six care managers who share the caseload of 67 clients. This includes a substance use disorder specialist; a vocational specialist who assists with employment; a nurse, and a supervisor. The doctor assigned to Homeless ACT is Psychiatrist Dr. Tracey Skale, the Chief Medical Officer for Greater Cincinnati Behavioral Health Services. "I've been with the Homeless ACT team since the beginning," says Skale. "I love working with all of the teams but this one always has had a special place in my heart. Clients on this team have every psychiatric illness but the common thread is homelessness."

GCBHS care managers are trained to help clients navigate what can be a very difficult process which can be very overwhelming and discouraging for someone with a severe mental illness. They also help clients make and keep appointments, plan and stick to a budget and ensure the clients are signed up for some type of income – typically social security disability.

The team helps people like Jason, who has schizophrenia, a neurobiological illness that affects one percent of the population. Until

recently, Jason has been living on the streets. No one knows specifically what happened but when a timeline was pieced together it appears that he was in an apartment for many years before simply walking away to live outside. What we do know is that around that same time, the building manager passed away. Whether or not that triggered something in Jason we can only surmise. But something did happen that made him unable to be surrounded by four walls.

According to Brandy, a care manager on the team, "Two years ago he refused to have any conversations about housing. He had serious issues with being inside due to his mental illness. In fact, he would prefer to live at construction sites because, in his mind, he was a construction worker and that's where he felt the most comfortable." The team supervisor Stephanie concurs, "It was baby steps. We had to develop that relationship and work on meeting his basic needs first. That allowed us to build a deeper trust. Once we earned his trust and kept it, he agreed to see a psychiatrist. But it definitely did not happen overnight."

So how did it happen? Stephanie explains, "He began to see Dr. Skale and established a relationship with her. Once that happened, he was more open to trying medication injections. That led to an improvement in engagement and symptom management, which caused a reduction in barrier symptoms and eventually led to the apartment." Since moving into his apartment, the team has noticed big changes in Jason. He has remembered how to clean and cook for himself, and he is even shaving! Brandy says, "We give Jason a lot of credit for his desire to be pro-active. Many times, now he's the one calling us to make sure his appointments have been made." She smiles, "It doesn't get much better than that!"

Jason has nothing but praise for the team, "The ACT team has helped me so much," he says. "I can't drive so they help me get around (some of the symptoms Jason experiences make it dangerous for him to drive). They've been like a family."

According to Dr. Skale, "It is with complete confidence I can say to the patient before me, 'we can help you' because from my years of experience, I know that the Homeless ACT team will do whatever it needs to do to help that person with his or her unique situation. I've seen it repeatedly.

We keep hope alive."



When someone goes undiagnosed with a severe mental illness such as schizophrenia and they do not have access to care, needs are not met, and symptoms escalate. Organizations, such as Greater Cincinnati Behavioral Health Services (GCBHS) in southwestern Ohio offer intensive support to these individuals who are often overlooked and some of the most vulnerable among us. The GCBHS Assertive Community Treatment (ACT) teams focus not only on treatment options, but also on other wrap-around supports that address basic needs. ACT teams are made up of multiple specialists whose combined goal is to advocate for the clients by accessing community resources. ACT teams focus on helping to stabilize the client and have them graduate to a lower level of care.

Schizophrenia and Support Groups

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Today, I realize that there is a time for people to grieve and find comfort with others who share a diagnosis. It's cathartic to cry when feeling discouraged and hopeless, and it can be helpful to understand that you are not alone in your suffering, and that precious friends can be found in surprising places. I am a firm believer that families should never give up. There is always a new medication on the horizon, new supplements and cutting-edge treatments. Today, experts in the field of schizophrenia are watching for at least two new medications on the horizon which have entirely new mechanisms of action for treating schizophrenia.

In my recovery, a few years ago, I started my own grassroots support group through the CURESZ Foundation to encourage and educate others. A CURESZ Board Member and professional counselor, Catherine Engle, worked with me to develop guidelines for attendees. At every meeting, a handful of people attend who are fully recovered from schizophrenia. Also on the virtual meeting, we have a few family members of people who have fully recovered. I find them to be greatly resourceful and encouraging. Struggling families are welcome to join us and ask questions to be answered by those on the call in recovery. Those who are thriving offer their own experience, relevant suggestions, and what worked best for them when they were at a point of life where they were struggling themselves, and also felt hopeless.

I am pleased with the way my support group functions and meets needs. Sometimes, I think I am the one who benefits the most. I have enjoyed watching it grow.

Never losing hope

Today, when I speak to groups of people with schizophrenia, I emphasize that hope is never lost. I concede that there is a time to mourn, but emphasize that there is also a time to fight, and celebrate even small accomplishments. And yes, today I do recommend support groups – the ones out there that offer both healing and hope.

Winged Being Six

Meghan J.M. Caughey (*Survivor*, page 2) is currently working on a series of drawings for her new book in progress titled "*Winged Beings: Marking Art from the Lap of the Universe.*"



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The drawings are pen and ink and charcoal on paper, 30" x 40". I just invite the images to arise from my unconscious, and they basically draw themselves. I learned this way of "free drawing" when I was briefly in training to become an art therapist. The unconscious draws the picture.

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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