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CURESZ FOUNDATION
Newsletter

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Comprehensive Understanding via Research and Education into SchiZophrenia

A Path to Meaningful Recovery

by **Alessandra**

I was recently asked what the experience of being the caregiver to a person with psychosis has been like for me and my answer was: *"It has made me a better human being."*

My words surprised me, because my body still remembers the visceral fear and the utter hopelessness I felt when my son disappeared from our home for days. Or when he would collapse to the floor asking me: *"Please make them (the voices) stop, these people who are yelling and harassing me."*

When my son first started to act in a bizarre and inexplicable manner, my family lost any sense of normality. Nothing made sense – our realities felt as altered as his. I felt hopeless when he accused me of poisoning his food. I didn't know what to say when he would point at his arm and tell me there were tiny creatures crawling underneath his skin. The effects on our household were conflict and isolation. What my family was facing is the dilemma shared by many families of a person experiencing psychosis. In an ideal world, we would have received the assistance of specialized teams[1] to support and guide us as a family unit. Whilst that is an option in the United States, these services are scarce and not easily accessible. To further complicate the matter, often the very person at the center of the distress is confused and unwilling to seek help. It is often up to us, the caregivers, at the frontline of the experience, to learn how to approach our loved ones with compassion, kindness and understanding, and build a relationship that can start our families on the path to recovery.

Alessandra

For my family, that happened when I read about the Psychosis REACH program (Recovery by Enabling Adult Carers at Home) or P-REACH program. This program has been developed at the University of Washington in collaboration with experts from Stanford University and Newcastle University and is based on principles of Cognitive Behavioral Therapy. Psychosis REACH is a community-based intervention developed with and for caregivers and its goals are to increase the ability of caregivers to relate with their loved ones, find mutual support and solidarity, and set the foundation for recovery.

At the core of Psychosis REACH is a set of communication approaches called the FIRST skills, with the main goals being to rebuild a connection with our loved ones and to reduce the distress and isolation they are experiencing. As part of my journey with Psychosis REACH, I connected with Angela, a psychosis REACH Family Ambassador who is a trained family peer. As she helped me strengthen my connection with my son, she shared with me how the Psychosis REACH program has changed her relationship with her adult daughter, Tara.

Angela, as a single mom, had spent years trying to find help for her daughter, with little guidance. Because of her psychosis, her daughter has been paranoid, which led to eviction. She was afraid of leaving the house and verbally abusive. Because she was unwilling to seek help, she was eventually court-ordered into treatment.

Angela was lost in the agony, frustration and heartache of wanting a good relationship with her daughter and a path of care and coping for herself. In the absence of guidance or community, her first approach was to try to "fix" Tara: she would arrange appointments, support groups, direct Tara on what to do, setting all of the rules, all the while living in a state of high anxiety about Tara's behaviors and mood swings.

In 2021 Angela took the Psychosis REACH training and learned the FIRST skills. With time, these communication skills changed their relationship. **Here's how Angela used the FIRST skills in her relationship with Tara:**

F: Falling Back on the Relationship

Angela focused on finding neutral topics of conversation, discussing positive shared memories, and highlighting Tara's strengths and goals. Her main goals were showing Tara that she was cared for and accepted, empathizing with her distressing experiences, and communicating the idea that her responses made sense given her reality. For example, instead of criticizing Tara for staying in her room most of the day, Angela might say, *"Tara, I love the way you set the table. I know it's hard for you to come out of your room since you've been so scared today. I remember all the times you've helped me in the kitchen. This brings back some really good memories, doesn't it?"*

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WhatSZ IN THIS EDITION

SCHIZOPHRENIA SURVIVORS

Kody Green

Kody Green was born in 1994 in rural Wisconsin. He has a younger brother and a younger sister, and a mother who struggled with schizophrenia throughout most of his life. He never knew his father, who died in a car crash when he was a year old.

Kody's childhood was difficult. He felt he was his mother's caregiver, and remembers having to *"grow up"* early on to look after her and his siblings. Throughout his childhood, he never had enough money, and pretended he was not hungry at school when he didn't bring a lunch. He remembers his mother's applications for financial assistance for low-income families.

Despite a difficult home life, Kody always did well in school, enjoying theatre and music, and running track and cross country. From a young age, he maintained a supportive circle of friends who made good choices and avoided alcohol and drugs. At age 15, Kody also met his future wife, Allyson, at a rival high school.

As Kody was finishing high school, in 2013, his mom was finally diagnosed with schizophrenia and began antipsychotic medication, but much cognitive damage had already been done.

Kody planned to stay home to care for his mother after graduating from high school but finally realized that his mother was stable enough for him to move on. He and Allyson decided to rent an apartment near Western Technical College in La Crosse, where Kody began classes to become a choir director or music teacher.

Kody did well until the end of his first semester of college, when he began to believe that other people were watching him, and that his wife was trying to sedate him through his food, with plans of *"putting him away"* in a hospital or psych ward. He refused to eat or drink anything he suspected she may have touched. He remembers hearing voices, which soon became overwhelming, and hearing other noises such as loud sirens that he eventually realized others could not hear. He saw people around him barely defined and faceless, and felt crawling sensations on his arms. Kody was very aware that his mother's schizophrenia was a genetic condition, and was always looking for signs of psychosis in himself. But when it actually began happening, he never suspected his problem was schizophrenia.

Terrified of falling asleep, and desperate to drown out the visions and voices, Kody turned to both prescription stimulant drugs and cocaine, which he bought from friends in La Crosse. Losing his cognition and ability to think rationally, he found himself failing his classes. Soon after, influenced by the drugs, and having not slept for over thirty hours, he accidently wrecked his car, and was badly injured. Following the crash, he entered the criminal justice system. He would go through a formal trial, and spend close to a year in jail, from 2014-2015.

While in jail, Kody began to suspect that something was physically wrong with him, and that it was serious. He recognized that he was having cognitive problems, and wondered if he had chronic fatigue syndrome. Though he was not suspecting he had schizophrenia, he lived with voices and delusions, believing that he was in a coma, and that life in the jail was not real. Isolation made his symptoms worse.

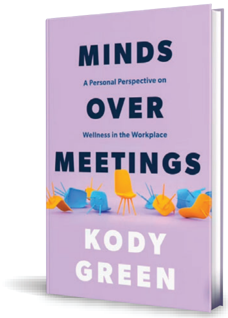
Because the correction officers at the jail saw Kody as a drug-seeker, his continued pleas for a physical assessment were ignored. But Kody spoke with other inmates and found that many of their stories paralleled his own. Kody remembers the other inmates recognizing he was unwell, protecting him, and making him feel safe. When he struggled the most, they provided the support he needed to stay out of the jail's psychiatric ward.

While in jail, Kody's mother and Allyson spoke with him over the phone every day. They visited him in person every other week, which was as often as they were allowed. On Kody's release, he was determined to work together with a physician to obtain a diagnosis and treatment for whatever was wrong with him. He soon began medication for schizophrenia.

Kody's first antipsychotic medication helped significantly, but he had side effects such as tardive dyskinesia, weight gain, anxiety and heart palpitations. He would spend five years going through various medication trials until he found one that worked well for him with the least side effects. Two years following his release from jail, he married Allyson and bought a house. Though Kody was committed to a psychiatric hospital for a few brief stays, both Allison and Kody's mom cared for him, preventing him from spending much time in psychiatric facilities.

As Kody recovered from schizophrenia, his goal was to find employment despite his criminal record. He finally landed a production job making cheese, where he worked for two years. He then worked for a year as an organic dairy retailer. During the beginning of the COVID pandemic, he changed jobs again to do customer service, and then began selling furniture, which he greatly enjoyed. While selling furniture, Kody was given flexibility with his hours, and was able to take extra time off if he was feeling symptomatic or needed extra medication.

In 2019, Kody put up his first personal video about his journey through schizophrenia on TikTok. The next morning, Kody woke up to see he had 10,000 followers. As the pandemic began, he recognized the great need for mental health resources on the internet, and found great fulfillment and success in making content that would educate and encourage people struggling with isolation, anxiety, depression, psychosis and other mental health conditions.


MINDS
A Personal Perspective on
OVER
Wellness in the Workplace
MEETINGS
KODY GREEN

Today, Kody's TikTok channel **"Schizophrenic Hippie"** has reached over a million followers. Kody left his job as a furniture salesman in 2024 to work full-time creating content and doing speaking engagements. Today, he has been featured in *USA Today* and *Men's Health*. Kody's proudest achievement is his recently released book: ***Minds Over Meetings: A Personal Perspective on Wellness in the Workplace.***

I Wish that I had been Educated about Schizophrenia

Bethany Yeiser, *President of the CURESZ Foundation*

When I began my undergraduate studies at the University of Southern California in 1999, everything was going well. I was concertmaster of their community orchestra on violin, working in a renowned biochemistry laboratory on DNA replication in bacteria, and was taking challenging classes, and scoring high grades. I was living my dream.

When I thought of *"mental illness,"* people whom I considered to be *"weak"* immediately came to mind. I didn't understand why the mentally ill did not just pull themselves together, be strong, and get over their problems. I was confident that I would always be strong, and never be held back from doing anything in my life that I really wanted to do. Essentially, at that time in my life, I knew almost nothing about brain disorders.

I also did not know that one in a hundred people will suffer with schizophrenia, and people with mental health diagnoses are everywhere and typically we are not privy to their diagnoses.

I thought of the mentally ill as having a lower IQ (which was entirely inaccurate) and imagined everyone with mental illness was eccentric in personality, dress and mannerisms. I had a picture in my mind of a mentally ill person, and that person was very different than me. I would soon find out I was wrong.

Not only did I know very little about brain disorders, but I also did not know that brain disorders do in fact run in my family. Though I know of no relatives with schizophrenia, I have three relatives who suffered for many years from treatment resistant depression, and there were two suicide attempts in the family, separated by many years.

But my relatives were not disabled. All three were highly successful professionals and enjoyable people. I hardly knew these relatives, but I was aware of their success. I'm confident no one outside of the immediate family knew of their struggles, though suicide claimed one of their lives.

After I was diagnosed with schizophrenia in 2007, eight years following my successful start at the university, I met privately with one of my relatives about mental illness. He confided in me that his greatest wish was to take his own life. However, he remembered a distant relative who had attempted suicide, unsuccessfully, and the attempt had left him impaired for the rest of his life. This relative was terrified he also would not be successful and would be left far worse off than he was before the suicide attempt. This prevented him from suicide.

But perhaps it was easier for my relatives to recognize their depression than it was for me to recognize my schizophrenia.

I wish so much that when my schizophrenia symptoms appeared in 2002, I had had the insight to recognize that something serious was happening in my life, but instead I strongly pulled away from everyone who loved and cared for me. I had never heard of delusions (fixed, false beliefs) and knew little about hallucinations or what paranoia looks like.

Today, it is my opinion that students in high school, or even younger, should be educated about brain disorders, including what the symptoms look like, and that they are treatable. They should understand that there should be no hesitation to seek help. And for many, the earlier a person begins treatment, the better they do, for life. I know this would have helped not just me, but my extended family members.

When I was in high school, we learned about healthy eating, getting enough sleep, safe sex/abstinence and exercise. My senior year, I was trained in self-defense and first aid. Education on brain disorders, however, was completely absent.

Looking back, I needed to learn that mental illnesses, including anxiety, depression, bipolar disorder and schizophrenia, are in fact physical (biological) problems. I did not know that schizophrenia was the result of an imbalance of neurotransmitters including dopamine, serotonin and glutamate, as well as many others, including some chemical involvement that is poorly understood by researchers. I was unaware that even geniuses could suffer from schizophrenia, but that many could succeed in life with the right treatment, personalized for each individual.

Most importantly, I had no idea that mental illness was something that I myself would soon be afflicted with, and would suffer from for many years before obtaining treatment and medication.

It would have been helpful to learn as a teenager about the symptoms of *"anosognosia"* as well, which is the absence of self-awareness and knowledge that a person is experiencing severe symptoms of schizophrenia or another serious brain disorder. Anosognosia is more than denial. It can happen in other physical problems, such as after a stroke, when the patient is left paralyzed but believes his arms and legs are working normally.

In 2020, the CURESZ Foundation established our first On Campus Club at the University of Cincinnati, in an effort to reach students of all majors with basic information about brain disorders. Today, CURESZ is proud to sponsor four small college clubs. We hope that the education we offer these students will enrich their lives and help them to be a support and true friend to struggling peers.

We must do better teaching our young people about these brain conditions that affect about one in five American adults, so they are prepared for whatever comes in life, be it mental illness in themselves or in people they love. And we must affirm that there should be no hesitation to openly talk about mental health and, if needed, to meet with a psychologist, counselor, doctor or nurse practitioner. Above all, young people must know that there is hope in treatment, and that counseling and medications can radically improve a person's life.

Much more work needs to be done.

~ Bethany Yeiser

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A Path to Meaningful Recovery

(continued from page 1)

I: Inquiring Curiously

With open-ended questions, Angela dropped her assumptions and let genuine curiosity lead her conversations instead of dismissing Tara's perceptions. In the face of Tara's fear and paranoia of the neighbors, she might say, *"I haven't really thought that our neighbor Bob is secretly spying on our movements. What makes you think that? Is there something that he's doing that is making you scared?"*

R: Reviewing What she had Learned

Building on the information she had gathered, Angela made links between the event and the subsequent thoughts, feelings and behaviors, so that they could come to a shared understanding of what was happening to Tara: "*Let me see if I have this right: Since last Thursday, you haven't been able to sleep. This morning, when you looked out of the window and saw Bob talking on his phone while he was looking at our side of the street, you thought that he was talking to the FBI and that's when you started feeling scared and locked all of the doors and shut all of the blinds. It sounds like you were feeling unsafe. Have I understood that right?"*

S: Skill Building

Once they have reached a shared understanding, Angela and Tara might think together about how she can feel less scared, which is a shared goal they both agree on. Angela said, *"Thank you for helping me understand what you felt. It's hard for me to keep the front door always locked because I need to open the door to let your little sister in. What if we try to brainstorm to find some ways for you to feel safe and for your sister to be able to come inside the house?"*

T: Try it Out

When Tara suggested that she could go in her bedroom and lock the door so that her sister could come in, Angela would respond to the idea saying: *"I like the way you came up with the idea of letting your sister in while you are in your bedroom. How would you feel about practicing this for a while, so you get used to it? You could put the date on the whiteboard every time you feel safe, and we'll see if you feel safe the next 5 times. What do you think?"*

Going through these skills was not a quick journey. It took years of trying, staying calm, and trying again. But over time, changes began to occur. Angela and Tara learned how to communicate respectfully, Angela acknowledged and appreciated her daughter's unique behaviors and thoughts, and she once again felt joy spending time with her.

In response to these changes Tara, feeling safer and understood, started her own journey to recovery, though it began 9 years after she first experienced psychosis. She started rebuilding her sense of self-esteem and her own identity. At this time, she has more positive thoughts about herself and feels like she has more control over her life choices. She now lives on her own without incidents with the neighbors; she leaves the house and goes to doctors or to get groceries; she sees a psychiatrist and receives counseling; she allows maintenance people into the house without fear; and Tara and Angela talk or text about their days positively and with respect. Most importantly, their conversations include Tara verbalizing her thoughts and behaviors and coping skills that she can use when she starts experiencing distress.

Angela's journey is no longer about *"fixing"* her daughter, but it's about enjoying their relationship. She has also learned self-care skills that have helped her when she feels fear, anxiety, and stress. Furthermore, she has become an advocate helping other families through the Psychosis REACH Family Ambassador Program[2] and with this *"community of care"* she is no longer alone.

In fact, Angela coached me in using the FIRST skills with my son and our understanding and communication have become honest and supportive. I am learning how to get closer to the truth, to respect and to be kind to myself and others, and to use meaningful, sensitive, and honest words. He recently told me *"Mom, I see you with a drive for understanding something that has affected me so much, and it makes me so happy!"* When I heard those words and saw his smile, I knew we were on the path of recovery.

References:

1. "Special Report: What is 'Coordinated Specialty Care' and Why Is It Effective?" https://psychiatryonline.org/doi/10.1176/appi.pn.2022.05.5.1.
2. "A thematic analysis investigating the inaugural psychosis REACH Family Ambassador Peer Training Program. https://www.dovepress.com/articles.php?article_id=90345.

PSYCHOSIS REACH
Recovery by Enabling Adult Carers at Home

For more information on Psychosis REACH and developing FIRST skills, please visit: **https://www.psychosisreach.org**

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.

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