

Your SMI Roadmap

by Nicole Gillen, author of "Schizophrenia & Related Disorders"

For a parent, navigating the challenges of serious mental illness (SMI), there is no roadmap. I learned this very early on when my child became sick with schizophrenia. I thought I understood how to work with doctors, follow the suggested treatment, and all would be well. But my child kept getting sicker, and she didn't understand she was sick. Mental health professionals didn't explain concepts like "anosognosia" to me or provide any clarity on the variety of symptoms she was experiencing. It was a murky, complicated, isolating, and frightening experience to figure out how to best help my child.

When dealing with serious mental illness, there is no typical or consistent path for the person with the illness, or the family trying to support them. The treatments are different, the issues are different, and to top it off – especially in the U.S. – each state is different in how they might support or engage with the individual. The permutations and challenges in stabilizing and creating a path are endless and confusing. In the U.S., the lack of consistency across the country means everyone needs to figure out the following areas on their own:

- Healthcare and hospitalizations
- Assisted Outpatient Therapy (AOT) and judicial engagement
- Legal support issues
- Disability / financial support
- Insurance / Medicaid
- The interface with the legal system
- Government support programs
- And more...

There is a way, however, to get clarity on what you might need to do as a caregiver. The following chart distills the key areas that all caregivers (or individuals with the SMI) need to potentially address over the course of the illness.

Areas of Consideration	
Beginning of the Journey	How to engage with hospitals, case managers, and more
	What to know when it comes to doctors
	Understanding treatment options
Key Management Tools	Learning how to communicate with your loved one and family, knowing key terminology that facilitates better treatment
	Finding support groups for yourself and your loved one
	Creating your ongoing paper trail
Could Happen Anytime	Being prepared for crisis situations: suicidal ideation, arrests, run away, etc.
	Navigating the legal system
	Securing housing and pre-empting homelessness
Getting the Right Support Setup	Setting up the right legal support: power of attorney, conservatorship, guardianship. Or even advance directives
	Importantly, setting up the best financial arrangements such as SSI, SSDI, or other government services
Long Term Issues	Diving into estate planning, special needs trusts & creating a Letter of Intent to ensure care continuity after you're gone
	Transitioning to autonomy for your loved one

The rest of this article will break down each area of consideration:

Beginning of the Journey

Hospitalization is complex, but caregivers can take proactive steps before their loved one requires hospital care to drive optimal treatment. This includes establishing a thorough paper trail, compiling outpatient records, and maintaining essential documents like photos. To prevent a bad outcome, there are strategies to consider such as pursuing hospitalization as early as possible to minimize damage to the brain and requesting long-acting injectables instead of pills immediately after discharge from the first admission to ensure treatment adherence. Additionally, caregivers may find it beneficial to establish a rapport with local law enforcement in anticipation of potential crises resulting from psychosis.

Upon hospitalization, collaborate with case managers to navigate various aspects of care. This may involve strategizing with authorities, such as exploring Assisted Outpatient Treatment (AOT) or advocating for favorable judicial outcomes if law enforcement was involved. Insurance coverage, outpatient treatment plans, and medication management also come into play during this phase.

Following discharge, caregivers continue to advocate for their loved one's well-being with medication management, treatment plans, housing, and supportive programs. Learning medical terminology and treatment options empowers caregivers to engage effectively with healthcare professionals, ask pertinent questions, and explore alternative care approaches.

Key Management Tools

Caregivers often face stigma surrounding serious mental illness when communicating with family and friends. Find resources and

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SCHIZOPHRENIA SURVIVORS



Jonathan Clemente



In 2022, I was awarded the Scott Adamson Memorial Peer Award from the Greater Cleveland Chapter of the National Alliance for Mental Illness. This honor was bestowed upon me in recognition for my outstanding efforts to share my lived experience with psychosis, helping others discover their own path to recovery.

~ Jonathan Clemente

I was born on the west side of Cleveland, Ohio in 1981. As a child, I generally enjoyed attending school and performed well academically. However, around the age of sixteen, because I felt socially isolated and desired to be a part of the popular crowd, I began to experiment with drugs and alcohol. Despite serving as a social lubricant, the use of substances came with many negative consequences. For example, I found it challenging to uphold my academic studies and during my junior year I ended up dropping all my AP and honors classes.

In 1999, following my high school graduation, I left Cleveland to attend Skidmore College in Saratoga Springs, New York. Finding it difficult to make friends without the social crutch of alcohol, I returned to my pattern of indulgence. Again, my GPA soon fell significantly. Sometimes thoughts of paranoia and feeling that the world was turning on me began to surface. Soon I began seeing a college counselor who started me on an antidepressant, but my substance use nullified its potential effect. Due to my declining performance and stability, I left Skidmore College to return to Cleveland, transferring to the Cleveland Institute of Art, which offered a five-year undergraduate program in the visual arts.

In the fall of 2003, in my fourth year at the Cleveland Institute of Art, after periods of heavy bingeing, my first psychotic hallucinations and delusions began. For example, my mind told me that I had been on the evening news, and I feared pending legal action against me for my behaviors while under the influence. In one class, I remember struggling to differentiate whether I was hearing voices in my head or if students were actively gossiping about me. Finally, I began to realize that if I did not quit drinking and drugging, both my mental stability and my future would be in jeopardy. Shortly thereafter, I began an intensive outpatient treatment program for chemical dependency.

In 2005, I graduated from the Cleveland Institute of Art. The stress of confronting a challenging job market peaked my anxiety, and I was briefly hospitalized for suicidal thoughts. During the next few years, I returned to school with the hope that math and science classes would be easier, since I was now sober. Challenged by the increase in stress over the demands of my coursework, I began to believe that God was communicating with me through license plate numbers on the back of motor vehicles. I imagined the license plate numbers giving me suggestions for how many hours I needed to study or mnemonic clues on how to succeed on the prospective exam.

In 2011, I met with a new psychiatrist who formally diagnosed me as having a psychotic disorder. He started me on a slew of different antipsychotics. Eventually, I adhered to an antipsychotic which seemed to be the most

effective medication with the least side effects, though it still gave me tremors. Despite my lack of insight into my mental illness, I regained my ability to concentrate and focus while on the antipsychotic. In 2012, about a year into this latest course of treatment, I approached my doctor with a request to discontinue the antipsychotic, which I still firmly believed I did not need. While my psychiatrist was opposed to the idea, he eventually consented. However, when I abstained from the antipsychotic, my ability to concentrate diminished again, and I became unable to continue my graduate coursework. For the next five years, I worked in a print shop as an assistant.

Finally in 2017, having been off all my antipsychotic medication for five years, I had a full-blown psychotic episode. I believed that my boss had put tracking devices underneath my car and I thought I had supernatural abilities. I imagined I could hear conversations through walls and somehow neurologically intercept communication signals over the internet. I was then transferred to a psychiatric ward for my longest hospitalization, two and a half weeks.

Following my discharge, I consented to follow the advice of my doctor and my parents to travel to Hopewell Therapeutic Farm, in Middlefield, Ohio, a residential treatment center for people with serious mental illness. I stayed there for the next ten months. During my stay, I resumed medication trials and was able to discover a series of medications with a lower side effect profile. My treatment team at Hopewell also helped me to search for suitable employment.

During my employment search, I came upon a job posting within Catholic Charities which listed having a mental or substance use disorder as one of the desired qualifications for employment. I interviewed for the position and in the interview openly shared about my psychotic episode. They decided to hire me and within a few months, I became certified by the state of Ohio to serve as a Peer Support Specialist.

I now work with young people who have recently had an episode of psychosis, and I serve as a mentor to advance their recovery goals. Since recovering from my last episode, I have enjoyed a busy and stable life as a Peer Support Specialist. In 2019, I also began consulting work with Northeast Ohio Medical University (NEOMED) and here I utilize my lived experience in recovery to advise mental health teams throughout the state of Ohio on the best treatment practices for people living with schizophrenia and other psychosis-related conditions.

For the last two years I have been in a serious romantic relationship and this past May of 2024 we were married. We look forward to spending our lives together.

Delusions

Delusions are defined as “fixed false beliefs.” They are a common symptom of schizophrenia and some types of depression and bipolar disorder.

Some scientists believe that, as your mind is decompensating, the brain creates an imaginary world of delusions to cope. Delusions vary widely from person to person, such as beliefs about secretly working for the CIA or that the government is out to get them.

One person may think a microchip has been implanted inside their body with a tracking device, as dramatically portrayed in the movie “*A Beautiful Mind*.” Another may experience religious delusions of grandiosity, believing they are the Messiah or a prophet. One of my friends living with schizophrenia believed that she could cure cancer, as well as many other diseases – all from the hospital room where she was staying as a patient.

I have experienced hallucinations and paranoia over the years. The biggest surprise I have found about delusions is their overwhelming power to take over your life, stealing you away from the real world. My delusions would eventually become so distracting that I was left unable to work and disabled. Finding a small pill to take every day that caused these delusions to disappear was also an unexpected and welcome surprise.

As a teenager, I spent much time daydreaming about where I would go to college and what I would study. Calculus was my favorite class in high school, and I was drawn to biomedical engineering. When I was awarded a scholarship to my dream school, the University of Southern California (USC), I was excited about my future there.

At first, things seemed to be going quite well. In my first semester, I took organic chemistry and other difficult classes. I also landed a job with a laboratory focusing on DNA replication in bacteria, and I was appointed concertmaster of their community orchestra on violin.

But something was very wrong.

As for the professor who ran the laboratory where I worked, humility was not his strong suit. He spoke often about how if only a certain set of experiments would work, leading to other results he genuinely expected to see, a Nobel Prize would be within his reach.

The lab was excellent, and the professor had been awarded millions to study DNA replication. However, a Nobel Prize was highly unlikely. Nonetheless, when he talked about it being within his reach, it was genuine to me, and it became my goal, too.

I found myself spending my time in the lab in the early hours of the morning and stopped studying much for exams. Often, I arrived to classes late, exhausted from many hours working in the lab at night. My grades dropped, but I didn't care, wanting to be a part of a team winning a Nobel Prize.

Throughout the summer after my first year of college at USC, I continued working in the lab. Looking back, I should have started a new project but was exhausted and emotionally unable to give the lab any more of my time. I soon left the lab, which had been my passion.

During the following year, my sophomore year of college, somehow, I got it together, taking challenging classes, including engineering physics and advanced biochemistry, and scored

high grades. But my dream was still that Nobel Prize, and as I realized it was not happening in the lab, I needed to find another way.

The fateful day of 9/11 occurred during the fall semester of my junior year. Watching the news, I continued looking for any opportunity to bring me money, fame, and influence. At that time, my church was sending a team of students to China to survey one of the poorest areas in the country. I eagerly applied for my first passport and planned for the trip. I was spending all my time online researching China, and my grades, again, suffered.

In China, after encountering people living in poverty, I began to rethink my life. Could I assist a million people living in China? Or perhaps millions? Was this my new mission?

When I was in high school, I was sure that, barring a car accident or terrible illness, I would almost certainly graduate from high school. In 2001, while traveling around China, I had the same degree of certainty that I could impact millions. And with a new dream for my life, I abandoned my love of science.

After returning to the United States from China, I took the easiest classes I had ever taken at the university and again received low grades. And instead of focusing on school, I spent all my energy planning my trip to rural Africa.

Still hoping to change the world, in the summer of 2002, I went to Nairobi for two months, spending most of my time living in poverty and without even enough food to stay healthy. I never provided my parents a phone number or address where they could find me, though I had promised them contact information.

While living in Nairobi for two months, I came to believe with even more certainty that I would make a worldwide impact. When I returned to college following my trip to Africa, I believed I was the next Mother Teresa and dropped out.

Today, I have been living in full recovery from schizophrenia for over fifteen years. Thanks to medication adherence, my drive to achieve the Nobel Prize has disappeared completely, as well as my dream to impact millions and become famous, as I understand these were delusional thoughts.

Instead, I seek to make a realistic impact as a mental health advocate by presiding over the CURESZ Foundation which I established seven years ago with my psychiatrist, Professor Henry Nasrallah, MD.

I currently enjoy living in my one-bedroom apartment near the University of Cincinnati. My life is filled with great relationships with my parents, many friends, and a loving church, where I play violin most weeks for services. I am content with a full and purposeful life.

I am amazed at how this illness of schizophrenia can consume a young person's life, leading to so many false expectations and impossible goals, which can feel so real.

Delusions are treatable. Today, I hope that I can attain perhaps an even higher goal than I had imagined before, which is helping others to find recovery from schizophrenia.



Bethany Yeiser
President of the CURESZ Foundation

This summer Bethany and Karen Yeiser are celebrating the tenth anniversary of the release of their memoirs *Mind Estranged* and *Flight from Reason*.



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Your SMI Roadmap

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support networks to combat this isolation and foster understanding for both you and your loved one.

Understanding terms like anosognosia, a neurological condition that makes it difficult for people to recognize their own health problems or neurological deficits, is crucial. Grasping concepts such as positive, negative, and cognitive symptoms enable caregivers to explore diverse treatment options tailored to their loved one's needs. This knowledge empowers caregivers in providing effective support.

Discovering the fundamentals for ongoing support of your loved one is vital.

Could Happen Anytime

The unpredictable nature of SMI can disrupt an individual's path to recovery. Psychosis can emerge suddenly, often left untreated due to limitations in psychiatric hospitals and emergency rooms, which may dismiss crisis-stricken loved ones as not meeting the threshold of "dangerousness," leading to dire consequences.

This could result in your loved one grappling with suicidal thoughts or fleeing due to auditory hallucinations. Alternatively, they may have encountered law enforcement during a psychotic episode, resulting in incarceration.

Regardless, it's a crisis, and as a caregiver, you're left scrambling to secure the necessary support for your loved one. Whether navigating the complexities of the legal system, seeking housing assistance, or accessing government programs, you need to be equipped with the knowledge and resources to navigate these challenges effectively.

Getting The Right Support Setup

Navigating disability-related services is far from straightforward, with each state imposing its own unique requirements and procedures. Whether you're pursuing Supplemental Security Income (SSI) or Social Security Disability Income (SSDI), it involves navigating through various hoops and ensuring you have the information readily available for a successful application.

Caregivers also face barriers posed by the Health Insurance Portability and Accountability Act (HIPAA). Many medical professionals cite HIPAA as a reason for limiting communication with caregivers, necessitating the establishment of some form of legal proxy to advocate effectively on behalf of your loved one.

However, even more daunting is the process of obtaining legal support through mechanisms such as power of attorney, conservatorship, or guardianship. If your loved one is over the age of 18 and experiencing severe anosognosia (lack of insight) or if they acknowledge their illness but refuse legal assistance, securing these legal protections becomes even harder.

Long Term Issues

Caregivers want to pave the way for our loved ones to achieve their best possible outcomes. This is where a comprehensive estate plan becomes crucial, involving the establishment of a Special Needs Trust and a Letter of Intent. These measures ensure that whoever assumes the caregiving role after you've passed away understands how to continue supporting your loved one effectively.

Ideally, your loved one will eventually achieve self-sufficiency, capable of managing all Activities of Daily Living (ADL). Identifying any personal challenges they may face, as well as establishing a realistic budget, are vital steps to foster stability.

In Summary

Crafting a personalized roadmap if you're living with schizophrenia, or for your loved one grappling with the illness, demands resilience, diligent research, access to information, and optimism. There's a valuable resource available to offer consistent guidance, options, and support, no matter where you reside in the U.S. with answers to these issues.

This resource comes in the form of a book titled "*Schizophrenia & Related Disorders: A Handbook for Caregivers*," readily accessible on Amazon and Barnes & Noble. Interestingly, while the book was tailored with the U.S. in mind, its insights extend beyond borders, addressing universal challenges associated with schizophrenia and related disorders.

Authored by Nicole Drapeau Gillen, a caregiver; this book serves as a comprehensive foundation for scenarios one might encounter. Whether you're embarking on the journey of understanding your loved one's needs or delving into long-term estate planning, the handbook equips you with essential information. Covering issues from initial diagnosis to long-term care, it serves as a reliable reference guide, offering insights to navigate the complexities of SMI caregiving.

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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