



Schizophrenia[®]
& Psychosis
Action Alliance

I'm Diagnosed. Now What?

A toolkit for navigating
the schizophrenia journey



PART ONE: GENERAL INFORMATION

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Introduction

This document was created with you in mind, offering tips and strategies specifically for those diagnosed and seeking guidance and support.

Being diagnosed with schizophrenia can feel overwhelming and isolating, but it's important to remember that you are not alone. This toolkit is designed to help you navigate the early stages of your diagnosis with practical advice, resources and encouragement. Together, we'll explore ways to understand your condition, manage your symptoms and take important steps toward recovery. Remember, there is hope! With the right support, you can lead a fulfilling and empowered life.

“You are not your illness. You have an individual story to tell. You have a name, a history, a personality. Staying yourself is part of the battle.”

— Julian Seifter



About Schizophrenia: The Basics

What does a diagnosis of schizophrenia really mean?

Schizophrenia is a brain disease characterized by three types of symptoms: positive, negative and cognitive.



“Positive” symptoms

Common types of “positive” symptoms are:

- **Delusions:** Strong, fixed beliefs that do not align with reality, such as thinking you have superpowers, are under the control of unseen forces or that other people or entities plan to harm you.
- **Hallucinations:** These experiences occur when you might perceive things that aren't there. These can occur in any of the five senses, but are most often auditory (you hear them) or visual. Auditory hallucinations can include hearing voices that comment on your actions, engage in conversation with you and/or give you commands. These voices can be any gender, familiar or unknown, and they can vary in tone and volume. Visual hallucinations can involve seeing shapes, colors or figures that others do not see. For instance, you might see shadows moving in your peripheral vision or vividly detailed people or objects that aren't really there.
- **Thought disorganization:** Difficulties organizing your thoughts, which can include confusing speech, jumping from one thought to another and/or illogical conversation. You may find it hard to explain your ideas and thoughts to other people.

Note: “Positive” symptoms do not mean they feel good! Rather, these are called positive in a more mathematical way: they are symptoms that are ADDED to what people in the general public experience. Similarly, negative symptoms are SUBTRACTED from what most people experience.

“Negative” symptoms

These include challenges with motivation, social withdrawal, low emotional expression, reduced speech, a loss of interest or pleasure in daily activities and difficulties with personal hygiene.

Cognitive symptoms

Cognitive symptoms are generally related to thinking and brain processing. For example, you might find it hard to concentrate on a task, remember important details or make decisions quickly. You also may struggle to follow a conversation, or forget an appointment despite setting reminders.



A schizophrenia diagnosis requires that at least 2 of these core symptoms must be present for at least 6 months, and must significantly impact daily functioning:

- **Delusions***
- **Hallucinations***
- **Disorganized speech***
- **Disorganized/catatonic behavior**
- **Negative symptoms**

**At least 1 of these specific symptoms must be present.*

Psychosis

Psychosis refers to a group of symptoms that affect the brain, causing a person to lose contact with reality. A person's thoughts and perceptions are disrupted and they may not understand what is real and what is not. An episode of psychosis can include delusions, hallucinations, incoherent speech and unusual behavior.

Psychosis symptoms are not unique to schizophrenia; they can occur with any abnormal brain function. Psychosis episodes can be experienced by people with other brain disorders such as Alzheimer's disease, autism and Parkinson's disease. People with traumatic brain injuries and those who have had strokes or other physical illnesses also may experience psychosis. Using certain substances (legal or illegal) also can lead to psychosis by altering brain function.

All of these symptoms can make it hard for you to live independently and maintain relationships. Many aspects of your life may be affected, such as school, work, friendships and family relationships. These symptoms can even make it challenging to engage in daily activities such as showering, brushing teeth and getting ready for the day. Other challenges can include managing finances, taking medications and social interactions. More information is included elsewhere in this toolkit about navigating schizophrenia as well as important considerations for achieving recovery and overall wellness.

To understand if any of this is happening to you and to recognize early warning signs, refer to “Questions to Understand Yourself and Your Symptoms” in Part Three of this toolkit.

How is schizophrenia diagnosed?

Healthcare providers use a manual called the Diagnostic and Statistical Manual Version 5, Text Revision (DSM-5-TR) to diagnose mental illnesses, including schizophrenia. You can see the full DSM-5 diagnostic criteria at the [National Institutes of Health website](#). As part of your diagnosis, a healthcare provider will likely ask you some questions about what you've experienced, look at your medical history and other related records and talk with people who know you.

Once diagnosed, you might find it difficult to say or self-identify that you have schizophrenia or a related disorder. Many people experience this, because the diagnosis tends to be stigmatizing and misunderstood. From what people read about or see in movies or on TV, they may have a false perception that people with schizophrenia are violent – when in fact, they are more likely to be victims of violence.

Having a schizophrenia diagnosis involves educating yourself about the facts. This section has the information you'll need to do that. You'll also find links to videos and podcasts at the end of this document, where you can learn the personal stories of people just like you who are living with this diagnosis.



What causes schizophrenia?

Scientists are still trying to understand all of the causes. Variations in our genes are thought to contribute to the risk of developing schizophrenia. Genetic factors interact with environmental and other factors to increase the risk. These factors can include exposure to infections before birth, severe stress during childhood or adolescence, trauma and cannabis use. S&PAA is involved in several national research projects that are seeking more insights into what causes the disease.

How common is the disease?

Schizophrenia and related psychosis disorders affect at least 1 in 100 people in the United States – about 2 million adults. We believe the prevalence of the disease is dramatically underreported, however, since people with untreated schizophrenia often live in settings that are difficult to survey, such as jails, homeless shelters and nursing facilities.

Will I ever recover?

With the right treatment and support, you can lead a fulfilling, productive and connected life. You may need lifelong treatment to manage your symptoms, and finding the treatment that works best for you can be challenging and take time. However, with proper treatment and support, you can thrive and even recover.

- It's important to find a treatment team you and your loved ones trust to guide your treatment journey.
- Starting treatment as early as possible – and staying on treatment – is critical to maximize your chances of remaining stable and achieving recovery.

Recovery often involves a comprehensive approach that prioritizes both clinical aspects (such as symptoms) and personal aspects of wellbeing. Recovery is also a continuum, showing up differently in different people.



Clinical recovery is the process of a significant reduction of symptoms. The ideal path to recovery is through collaborative development of a treatment plan that includes medication, psychotherapy and regular monitoring by mental health professionals.

Personal recovery extends beyond clinical treatment to include social support, lifestyle modifications, work-related rehabilitation, skills training and a strong support system. Personal recovery can include key components such as:



Open communication with loved ones and participation in support groups for emotional support, practical advice and a sense of community.



Building a routine that incorporates healthy habits, such as regular physical activity, balanced nutrition and sufficient sleep.



Exercise to release endorphins, which are natural mood lifters and can provide a healthy distraction from stressors.



Goal setting to provide measurable ways to see progress over time and provide motivation when day-to-day progress is difficult to see.



Education about the disease to empower you to take an active role in your recovery journey.

The goal of these treatment elements is to enhance overall quality of life, promote independence and support long-term stability and resilience.

Anosognosia: The inability to understand you are sick



About half of people with schizophrenia and related psychosis disorders do not take their prescribed medications. One common reason is anosognosia, a neurological symptom in which people are unaware they have the disease, and as a result, are unable to understand that they are sick and need treatment. Many people living with schizophrenia experience at least a period of anosognosia, which is possible to overcome.

Anosognosia can be not only frustrating, but dangerous – leading to severe episodes of psychosis and causing trauma for both you and your loved ones. To make things worse, most people – including many healthcare providers! – have never even heard of this challenging symptom. As a result, people may misunderstand the behavior of a person with anosognosia. The symptom also may be overlooked in diagnoses and not properly addressed as part of the overall treatment plan.

LEAP (Listen–Empathize–Agree–Partner) training, developed by Dr. Xavier Amador, is one way to help caregivers use evidence-based communications tools to build trust with their loved ones that can lead to treatment. You can share the LEAP communication framework with your loved ones and friends to help them support you if you experience anosognosia. LEAP training is provided through the Henry Amador Center on Anosognosia; for more information, visit <https://hacenter.org/online-trainings>



Tools for addressing anosognosia

Living with schizophrenia and experiencing anosognosia can feel overwhelming, but it's important to be patient with yourself. Try to keep an open heart and mind, even when it's difficult. Begin by gently considering the observations of those who care about you. Your loved ones might mention certain behaviors or thoughts that keep occurring, unusual body movements or saying things that don't make sense. With time, these things may become noticeable to you and may help you understand and acknowledge your condition. This can, in turn, pave the way for more effective treatment and a stronger path to recovery.

Asking yourself the right questions can help you understand the situation better and improve your relationships with those who care about you:

- Have my loved ones told me that I need treatment for being sick, but I don't think I am sick?

- Do I ever feel like my loved ones don't understand what I am experiencing?

- What questions can I ask my loved ones to better understand their worries?

- Can I think of specific instances where they have noticed changes in my behavior or mood?

- How do I usually respond when someone tells me they are worried about me?

- What steps can I take to explore their concerns without feeling defensive or upset?

- What are some reasons I might resist the idea that I have a disease?

- How do I feel about the idea of seeking a professional opinion about my health?

These questions are designed to foster empathy, self-reflection and open communication, helping you bridge the gap between your experiences and your loved ones' observations. Exploring these questions can help you better understand the reasons behind their concerns, clarify misunderstandings and express your feelings constructively. The goal is to build a foundation of trust and mutual respect, allowing you to find common ground that supports your recovery.

Treatments for Schizophrenia

With proper treatment, people with schizophrenia can recover and thrive. The earlier treatment begins, the better the long-term outcomes tend to be. However, treatment at any point can make a meaningful and significant difference in your recovery journey. Treatment should be a dynamic and ongoing process, as your needs will likely change over time.

Effective treatment for schizophrenia and related psychosis disorders includes **medication, psychological therapy** and **supportive services** such as employment and education support. An ideal treatment program involves all three of these interventions, as well as other elements such as exercise and social support.

If you're in your first few years of having schizophrenia, coordinated specialty care (CSC) clinics can be an excellent choice. However, not all states have these clinics. CSC clinics are well known for providing best-practice comprehensive services (see page for more details).

Medication

Medication, and specifically antipsychotic medication, is typically the first treatment a healthcare provider will prescribe for schizophrenia. Medications can play a significant role in creating the foundational components of a recovery journey.

Antipsychotic medications differ in how they are given (some may be a daily oral pill, while others are given as an injection that can last for several weeks or months). You may have to try many different medicines before finding the best treatment for you.

There are two broad types of antipsychotic medications:

- **First-generation or “typical” antipsychotic medications.** These older medicines can effectively help manage symptoms for some people. However, they can have more severe side effects, such as intense body stiffness, involuntary muscle movements, blurred vision, sedation, dizziness and/or drowsiness.
- **Second-generation or “atypical” antipsychotic medications.** These medicines are more commonly prescribed today because they tend to have less-severe side effects than first-generation antipsychotic medications. However, many second-generation medicines also can cause side effects, including those listed above as well as weight gain and increased cholesterol and blood-sugar levels.

There are strategies to address the side effects of schizophrenia treatments that you can discuss with your doctor, including changes in nutrition and exercise and supplemental medicines.

For examples of these medicines and links to more information about them, visit <https://sczaction.org/treatment/>

Important: Never reduce or discontinue your schizophrenia medication on your own. Making changes to your dosage abruptly and without medical supervision may lead to a symptom relapse or other health issues. If you're experiencing difficulties with your medication or feel like you no longer need it, always talk with your doctor or other trusted person first.

Psychological therapy

Both individual and group therapy are considered vital ongoing treatments for you and your loved ones. They are crucial for “re-entering” community life after the disruption that schizophrenia and related psychosis disorders often cause. Psychological therapy can provide:

- Personalized education about/ understanding of symptoms.
- Strategies for reducing stigma, coming to terms with the diagnosis and coping with the condition overall.
- Strategies to establish and maintain personal and professional goals.
- Skill building (such as help identifying symptom triggers and improving adherence to medication).
- Crisis planning support.
- Social support and connection.

Key types of evidence-based psychological therapy are:

- **Cognitive behavioral therapy (CBT) for psychosis:** A structured therapy that helps you navigate psychosis disorders through challenging and modifying your unhelpful and ineffective thought patterns and beliefs to reduce distress and improve functioning.
- **Cognitive remediation:** An approach that aims to enhance cognitive skills such as memory, attention and problem solving.
- **Psychoeducation:** Education and support for you and your family members to better understand and cope with your disease.
- **Illness self-management training:** Equips you with self-management skills and strategies, such as relaxation techniques and symptom tracking, to cope with your symptoms and improve your overall wellbeing.
- **Social skills training:** Focuses on enhancing interpersonal and social functioning, helping you develop effective communication and relationship skills.



Supportive services

You also can benefit from the following support for your daily needs:

- **Supported education and employment programs** help you pursue educational and employment goals, providing hands-on, practical support with each step of the process. With best-practice approaches, the only requirement for participation is that you would like to return to school or work.
- **Peer support services** are delivered by others with lived experience of psychosis and/or schizophrenia who are further along in their recovery journey. Peer support specialists provide empathy and guidance to help you address the challenges of the disease.
- **Supported housing initiatives** can help you find stable housing according to your level of need. Housing resources can be found in Section Two of this toolkit.

Early intervention: Coordinated Specialty Care

If you're within the first few years of your diagnosis, coordinated specialty care (CSC) clinics provide some of the best practices in comprehensive services. CSC clinics are evidence-based programs that provide wraparound services under the same roof. Many include medication management, individual/group psychotherapy, family education, peer support, supported employment services and education guidance. This early-intervention approach can greatly improve quality of life and treatment outcomes and offers real hope for clinical and functional recovery.

Unfortunately, not all states have CSC clinics. Below are several online resources to search for CSC clinics and services near you:

- **Early Psychosis Intervention Network (EPINET)**, which features a map of early psychosis clinics in 17 states: CA, CT, FL, IN, LA, MD, MA, MI, MN, NY, OH, OK, OR, PA, SC, TN and TX.
- **Psychosis-Risk and Early Psychosis Program Network (PEPPNET)**
- **SAMHSA's Early Serious Mental Illness Treatment Locator (ESMI)**





Strategies to Manage Symptoms of Schizophrenia

Stress reduction improves all aspects of recovery

Long-term stress can worsen symptoms of schizophrenia and related psychosis disorders, making stress reduction an essential part of recovery. Here are some stress-management techniques you can try:



1. Establish a consistent daily routine: Regular schedules for sleep, meals, medication and activities provide structure and predictability, which can reduce anxiety and create a sense of stability.



2. Practice relaxation strategies: Deep-breathing exercises, meditation and progressive muscle relaxation can help manage immediate stress responses and promote overall emotional wellbeing.



3. Establish an exercise program: Start with activities you enjoy, such as walking in the park, dancing to your favorite music or practicing gentle yoga. Aim for at least 30 minutes of physical activity most days of the week, but remember to listen to your body and rest when needed. Setting small, achievable goals, such as 10-minute or 1-minute intervals at a time, can build your confidence over time.



4. Build a supportive network of friends, family, colleagues and mental health professionals: Trusted individuals can offer emotional comfort, companionship and practical help, making your daily challenges more manageable. They also can provide a listening ear, helping you to process your emotions and experiences. Mental health professionals can provide expert guidance and coping strategies tailored to your needs.

Coping with general symptoms

Understanding and managing early warning signs of a psychosis episode or other major symptom can be empowering and vital for your recovery journey. The most crucial step is to communicate these symptoms with your doctor and treatment team. They can provide valuable insights, modify your treatment if necessary and offer additional support to help you stay well. Be sure to include any people you trust to help support you in coping and managing the symptoms.

Strategies for coping with schizophrenia symptoms tend to fall into two categories: self-care and distraction. Using a combination of techniques from both categories can be useful.



Managing mood: If you notice changes in your mood that could signal the onset of a psychosis episode, integrating music into your daily routine might help. Music has the power to soothe and stabilize emotions, especially when they go too high or too low. Choose songs that create a sense of calm and happiness for you. Creating a playlist of these tracks can serve as a therapeutic tool, ready to play whenever you feel the need to manage emerging symptoms. Listening regularly also can help you maintain a sense of wellbeing and help prevent more severe mood swings.



Managing hallucinations: Begin by acknowledging the experience without judgment. Understand that these hallucinations are symptoms of your disease and not reality. Engage in grounding techniques, such as describing your surroundings aloud or a tactile activity such as squeezing a stress ball. Create a routine that includes regular check-ins with yourself. During these self-assessments, note any new experiences or intensified hallucinations, whether visual, auditory or tactile. Keep a diary of when the hallucinations occur, their content and what you were doing at the time for insights into possible triggers or patterns. Share this diary with a healthcare provider to inform your treatment plan.



Managing distorted thoughts or delusions: Start by acknowledging these thoughts as a common symptom of your disease, not reality. While vivid and compelling, these thoughts can create confusion or lead to actions that may not be safe or helpful. Practice grounding techniques, which can involve focusing on physical sensations or objects around you to bring yourself back to the present moment. Journaling your thoughts and discussing them with a therapist or other trusted support person can help you differentiate between what's a delusion and what's real. Over time, these strategies can improve your ability to recognize and correct distorted thoughts.



Managing through art: Creative activities such as drawing, painting or coloring can be a powerful tool in managing early warning signs of psychosis. These activities allow you to express thoughts and feelings that might be difficult to articulate verbally. The process of creating art can provide a sense of accomplishment and control, offering a constructive way to channel your emotions and reduce stress. Incorporating regular art sessions into your routine also can help you monitor changes in your mental state. For example, you may find that certain colors or themes keep appearing in your work when you're beginning to feel unwell. Keeping a visual journal can help you spot patterns and take proactive steps.

Additional coping tools for delusions and hallucinations

When you're confronted with thoughts that others are telling you are delusions, the first step is to acknowledge the emotions and confusion this can create. These thoughts can feel incredibly real and overwhelming, even if they seem strange or unbelievable to others. Many people with schizophrenia and related psychosis disorders experience these feelings.

Start by grounding yourself with simple exercises such as deep breathing, focusing on your surroundings or holding a comforting object. This can help anchor you and provide a moment of clarity amid the confusion.

Next, challenge these thoughts by examining the evidence for and against them. This can be done through a process called "**reality testing**." Ask yourself questions such as, "What evidence do I have that this thought is true?" and "What might be an alternative explanation?"

It can be helpful to write down your thoughts and the evidence you gather. Consulting with a trusted friend, family member or mental health professional can provide an outside perspective that can help you see these thoughts in a new light.

Reality testing also is a helpful tool for managing hallucinations:

- When you hear a voice, check to see if others around you hear it, too. For example, if you're at a coffee shop and you hear someone calling your name, ask a friend if they heard it, as well.
- For visual hallucinations, such as seeing a person or object in your room, try closing your eyes or turning away for a moment. Real objects or people will still be there, while hallucinations may disappear.
- In some cases, animals (such as dogs), can be trained to help you differentiate hallucinations from reality.
- Another technique is to use technology: record the sound you're hearing or take a picture of what you're seeing and review it to see if it was real. Hallucinations won't show up in a photograph, video or audio recording.

Delusion	Test Question
Believing you have special powers, are famous or have exceptional abilities that others do not.	Ask yourself, "What evidence supports this belief?" Compare your abilities to objective standards or feedback from others.
Thinking others are out to harm you, are spying on you or are plotting against you.	Consider whether there is any concrete evidence for these fears. Ask, "Is it possible I'm misinterpreting the actions of others?"
Believing that insignificant remarks, events or objects are significant to or directed at you.	Question the basis for these beliefs: "Is there a reason this would specifically relate to me?"

Managing cognitive challenges

It's very common to experience cognitive challenges when living with schizophrenia and related psychosis disorders. You might find it hard to concentrate on a task, remember important details or make decisions quickly. You may struggle to follow a conversation or forget an appointment despite setting reminders. This can be frustrating, but it's a common part of the condition that can be addressed and improved over time with the right strategies.

Practical strategies for overcoming cognitive challenges include:

- Organizational tools such as planners, calendars and reminder apps to aid memory and task management.
- Establishing routines and breaking tasks into smaller, manageable steps to help reduce your “cognitive load” and make daily activities more achievable.
- Creating checklists for routines, such as morning and evening tasks, to streamline daily activities and reduce cognitive load.
- Visual aids, such as color-coded labels and charts, to make navigating complex tasks and environments easier. (For example, using different-colored folders or bins for various types of paperwork can simplify organization and retrieval of important documents.)

Cognitive remediation programs, often available through coordinated specialty care teams, provide tailored exercises to improve memory, attention and problem-solving skills. Neuropsychological evaluations also can be helpful for identifying cognitive challenges and strengths and providing personalized recommendations.

Overcoming negative symptoms

It's common to experience negative symptoms, such as decreased levels of motivation or feeling like you don't want to be a part of activities. You may experience lower levels of emotion when watching videos, TV shows or movies. You may forget daily hygiene tasks such as brushing your teeth or showering. Although this can be frustrating, these symptoms can be addressed with a combination of strategies:

- **Engage in structured and meaningful activities** that can help increase your motivation and improve your mood. Try setting small, achievable goals for daily tasks; participating in hobbies or other interests; and gradually increasing your social interactions.
- **Cognitive Behavioral Therapy (CBT)** provides guidance in identifying unhelpful thought patterns and developing healthier ways of thinking and behaving. Working with a CBT therapist, you can learn strategies to challenge negative thoughts, set small achievable goals and gradually re-engage in activities you once enjoyed. This therapy encourages setting realistic goals and slowly reintroducing enjoyable activities into your routine.
- **Support groups and peer-led programs** provide valuable opportunities for social connection and mutual support, helping you feel less isolated and more understood. You can gradually integrate these strategies with medication management and regular follow-up with healthcare providers. This combination can help create a comprehensive plan to effectively combat negative symptoms and support long-term recovery.

Connecting with others

Building supportive relationships helps create a network of understanding and encouragement, which is crucial for managing your schizophrenia symptoms and fostering a sense of belonging. Engaging with peers, family, friends and/or support groups provides a safe space to share experiences, gain insights and receive emotional support. By reaching out to others, you create a network of understanding and encouragement that can help you navigate challenges and celebrate successes.

You can learn more about our S&PAA support groups starting on page 21 of this toolkit and on our website: sczaction.org.



Building and maintaining a social life with schizophrenia and related psychosis disorders can be challenging – but it’s possible with the right support and resources. These connections can give you strength, resilience and hope – essential components for thriving and recovery.

Develop a routine

- **Regular outings:** Set a schedule for regular outings, such as going to a café, library or park.
- **Community events:** Attend events such as farmers' markets, festivals or local fairs to find opportunities for casual socializing. These can be found through word of mouth or online platforms such as Facebook or Eventbrite.

Leverage technology

- **Social media:** Platforms such as Facebook or Instagram can help maintain connections with friends and family.
- **Virtual meetups:** Apps such as Zoom or Skype offer “virtual hangouts” you can set up with friends and family to make socializing more accessible.

Engage in hobbies and interests

- **Joining classes or clubs** based on interests (art, music, sports, exercise etc.) can help build social connections around shared activities.
- **Volunteering** can provide a sense of purpose and opportunities to meet people with similar values.

Connect with family and friends

- **Encouraging family involvement** in social activities can provide a supportive network.
- **Keeping in touch with friends** through regular calls, texts or meetups helps maintain existing relationships.

Practice social skills

- **Working with a therapist** on social skills training can help build confidence and improve interactions.
- **Practicing social scenarios** with a trusted friend or therapist can make real-life interactions easier.

Navigating Healthcare Laws: Important Options

HIPAA Waiver of Authorization

Taking charge of your treatment plan involves understanding healthcare laws such as HIPAA (the Health Insurance Portability and Accountability Act of 1996). HIPAA is designed to protect your privacy and give you control over your health information. It allows you to decide who can access your medical information that is held by your doctor, hospital or insurance company.

However, HIPAA restricts your caregiver and/or family members from having access to your health information. If you want them to have access, you will need to complete a legal form called a HIPAA Waiver of Authorization. This gives healthcare providers and others permission to share your health information with others – which can be important in supporting your care and getting you the treatment you need.

Important Note: Many HIPAA authorization forms must be renewed after a certain period – typically a year – and must be renewed with each facility where treatment is provided. Remembering to renew these forms is critical to ensure continuity of care, particularly in a time of crisis.

Learn more about HIPAA here: <https://www.treatmentadvocacycenter.org/resources/hipaa/>

Talking with your providers about HIPAA

Asking the right questions helps ensure you are informed and in control of your personal health information. Talking with your healthcare provider about HIPAA can help you understand who can access your information, the purpose behind sharing it and the potential impact on your care – and help you feel more secure in your treatment journey. Questions you may want to ask your healthcare providers include:

- How will my personal health information be used once I sign the HIPAA Waiver of Authorization, and who will have access?
- What safeguards are in place to protect my information from unauthorized access?
- How will signing this waiver impact my current and future medical treatment?
- How will signing this waiver affect my involvement in my own treatment decisions?
- Can I have a copy of the waiver and any documents explaining my rights and protections?

Remember, you have the right to choose what information to share and with whom. Deciding to sign a HIPAA Waiver of Authorization can help your support team ensure you get the best care possible.

Note: Even if you don't have a signed Waiver of Authorization at the time of a health crisis, HIPAA does allow your loved ones to communicate helpful information to doctors and other clinicians about your symptoms and recent events.

Power of attorney

A power of attorney (POA) grants a trusted person the authority to make important decisions for you if you're not able to. (It can be withdrawn when no longer needed.) This legal tool empowers those with POA to manage your treatment plan and interact with healthcare providers and insurance companies on your behalf. This tool can help ensure that your care remains consistent and in your best interests, providing a secure foundation for your wellbeing.

Guardianship/Conservatorship

These legal tools create a legal safety net, where someone you trust is appointed to help you make important decisions – particularly at times when your disease affects your judgment.

This support can be invaluable in managing your daily life, medical care and finances. It's important to remember that this arrangement is not about taking away your freedom; it's about ensuring you have the support you need to thrive. A guardian's role is to act in your best interest, and you still have the right to be involved in all decisions affecting your life.

It's important to research how your state defines and applies conservatorship and guardianship, as these laws and procedures can vary significantly across different regions.

To learn more about how these work in your state, search online using terms such as “guardianship” or “conservatorship” followed by your state; look for websites that use “.gov” or “.org” in the URL to find sites linked to government agencies and nonprofit organizations.





Civil commitment

Facing civil commitment can be a daunting experience, but understanding the process can help you feel more secure. Civil commitment occurs when a court mandates treatment for someone with severe mental illness who is a danger to themselves or others. The primary benefit of civil commitment for people with severe mental illness is increased safety for both the person and the community. By providing immediate access to treatment, civil commitment can help manage acute symptoms and prevent crises. This can lead to better long-term health outcomes, including improved mental health stability and a reduced risk of future hospitalizations.

However, the emotional toll of being committed against your will can complicate the recovery journey, highlighting the need for compassionate and person-centered approaches. Remember, you have the right to legal assistance, and it's important to stay connected with your support system as well as seek guidance from mental health advocates.

By being proactive and informed, you can better manage the emotional and practical aspects of this process to help ensure your needs and preferences are respected.

Learn more about civil commitment from this resource at the National Library of Medicine: <https://www.ncbi.nlm.nih.gov/books/NBK557377/>

Assisted outpatient treatment (AOT)

Assisted outpatient treatment (AOT) is a legal mechanism designed to ensure that people with severe mental illness receive the treatment they need while living in the community. AOT involves a court order that requires outpatient treatment for people with severe mental illness who have a history of not taking prescribed treatments on their own and have experienced repeated hospitalizations or incarcerations as a result. The goal of AOT is to improve adherence to treatment plans, reduce the frequency of psychiatric crises and enhance overall quality of life for people with schizophrenia and other severe mental illnesses. This approach balances the need for personal autonomy with the necessity of ensuring safety and stability, providing a structured support system that includes regular appointments with mental health professionals, medication management and community-based services.

Learn more here: <https://www.tac.org/what-is-aot/>

Schizophrenia Resource Line & Support Groups

S&PAA provides many support groups for people with schizophrenia and related psychosis disorders and their care partners, as well as a Resource Line (phone and email) for navigating the many aspects of schizophrenia.

Engaging with a resource line or joining a support group can empower you, offer validation and provide essential tools and strategies for navigating your recovery journey with confidence and resilience.

Resource Line

Schizophrenia & Psychosis Action Alliance offers a free information Resource Line with team members who can provide personalized information and resources to you and your families. We provide information and support to help navigate the complexities of your situation. We can answer your questions, connect you with tools and resources and help you find support services.

S&PAA does not provide medical advice or legal services, so we cannot make appointments or direct referrals. However, our team will provide you with encouragement, support and assistance.

Important: The Resource Line is not a crisis line. If you have thoughts of self-harm or are in a crisis you cannot handle alone, go to a hospital emergency room or dial the National Suicide and Crisis Lifeline at 988.

S&PAA operates a toll-free telephone Resource Line that anyone can call to leave a message:

1-800-493-2094

Calls are returned Monday-Friday between 9 am and 5 pm ET.

You also can reach our Resource Line via email through the Contact Us form on our website.



"Vulnerability sounds like truth and feels like courage. Truth and courage aren't always comfortable, but they're never weakness."

— Brené Brown.

Support groups

Peer support groups

We offer peer support groups for people like you who are living with schizophrenia or a related disease. We offer more than 35 hours of monthly virtual support groups in the United States. Those who have not been officially diagnosed with schizophrenia but have experienced psychosis also are eligible to participate.

Families for Care (FFC)

Families for Care is a support group for families of people diagnosed with schizophrenia or a related disease. Since its founding in 2008, Families for Care has reached thousands of caregivers who seek guidance about their loved ones with psychosis spectrum disorders and community with those who share their experience.

To learn more, register and receive information on days/times, visit:

<https://sczaction.org/peer-support-groups/>



Online communities

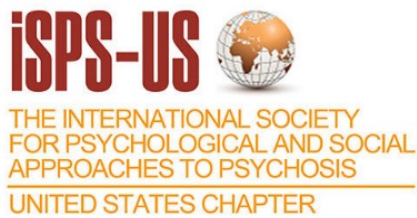
Online communities provide safe spaces where you can connect with others who share similar experiences, exchange coping strategies and find comfort in knowing that you are not alone in your journey. By engaging with these communities, you can gain insights from peers who truly understand what you're going through.



Families of Schizophrenia Support Group (Facebook): This Facebook group is an emotionally supportive community designed primarily for caregivers of people with schizophrenia, but also welcomes those like you who are diagnosed with the condition. The group focuses on providing a safe, supportive space to share frustrations, anger and hurt without judgment in a respectful environment. Joining requires answering membership questions to ensure a safe and dedicated community centered on guidelines that protect privacy and confidentiality.



Inspire | Health and Wellness Support Groups and Communities: S&PAA partners with Inspire to provide a space devoted to schizophrenia and psychosis support. Inspire provides a virtual discussion platform for members to write posts about their experiences, concerns and successes. Other members can weigh in and offer their perspectives or answer questions. Both you and family members can share your perspectives in the written discussion threads.



International Society for Psychological and Social Approaches to Psychosis, US Chapter: While medicine plays a key role in recovery, social and psychological support also are needed for a well-rounded recovery journey. ISPS-US promotes these additional approaches by providing education, training, advocacy and opportunities for dialogue among service providers, people with lived experience, family members, activists and researchers. ISPS-US provides community-building discussion, peer-reflection groups, networking opportunities and mutual support.



Reddit – r/Schizophrenia: This online community with about 80,000 members provides a space for the open discussion of schizophrenia-related issues (including psychosis symptoms in general, schizoid, schizotypal and paranoid personality disorders). This Reddit discussion space provides engaging threads across 30+ category “flair” topics, including Advice/Encouragement, Therapist/Doctors, Work/School, Medication, Progress/Good News, Delusions and Relationships. Users have the option to browse and post anonymously to protect their privacy.



Students with Psychosis: Students With Psychosis organizes in-person programming at local and regional levels and provides more than 160 hours/month of virtual programming at no cost to student leaders and advocates, with at least five hours facilitated each day and opportunities to get more involved. Students living with psychosis can join for free and get access to a Discord platform, daily office hours, virtual study hall, outreach support and project opportunities for leadership development.



Team Daniel Running for Recovery: With more than 4,400 members, this Facebook community is for advocates, prescribers, family members and anyone diagnosed with schizophrenia who wants to learn more about the antipsychotic medicine clozapine. Anyone looking to support themselves or a loved one can join, regardless of their specific treatment plan. Team Daniel’s core purpose is to help families and people like you navigate toward meaningful recovery from schizophrenia and related psychosis disorders through leveraging the latest health information about approaches to treatments that work.

Educational Resources & Bonus Content

This section features free resources to help you navigate recovery. It includes books, podcasts, webinars and videos. Choose the format that works best for you and matches your current ability to digest information.

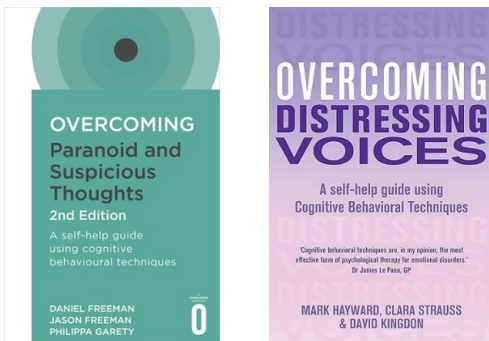
If you feel overwhelmed, take a break and return when you feel ready. As you progress in your recovery journey, your focus will improve.

*“If you can’t fly, run.
If you can’t run, walk.
If you can’t walk, crawl,
but by all means,
keep moving.”*

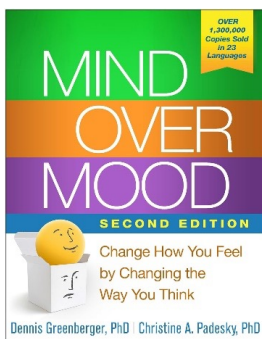
— Martin Luther King, Jr.

Books for Self-Help

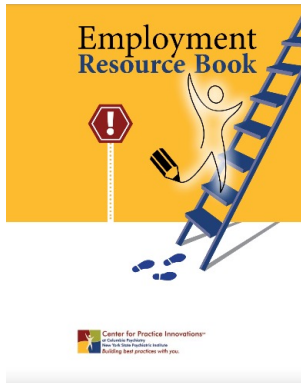
These books may be helpful in navigating your journey to recovery and provide actionable advice. They can be found for free at most local public libraries; heavily discounted **thrift editions are available on Thriftbooks**. Some local mental health organizations also may have these books available for members to borrow:



Overcoming Paranoid & Suspicious Thoughts and **Overcoming Distressing Voices**: Self-help books that can help you understand how to use cognitive behavioral therapy (CBT) strategies to navigate these common symptoms.



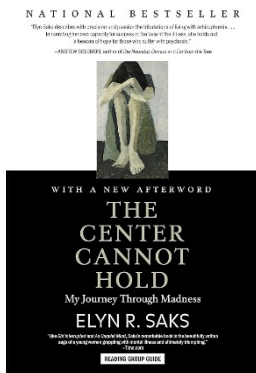
Mind Over Mood: Change How You Feel By Changing the Way You Think overviews the fundamental principles of CBT for managing the mood swings that people with schizophrenia often experience. Using evidence-based methods, this self-help workbook shows readers how to improve their lives using cognitive therapy principles across easy-to-use pages.



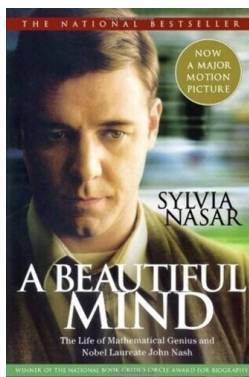
OnTrack’s Employment Resource Book details how regardless of age, you can prepare yourself to find work and succeed in workplace settings. The book details important considerations and common questions for each of the main stages of job hunting while managing a mental health condition: Prior to Job Search, During Job Search and After Getting a Job.

Books for Hope

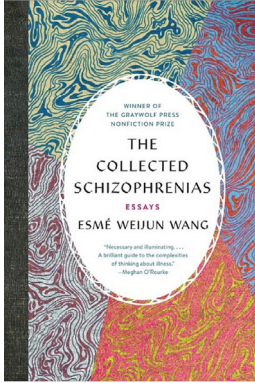
These books feature stories of recovery that show the life journeys of others with this diagnosis and their path to recovery.



The Center Cannot Hold: Dr. Elyn Saks is a law professor and expert in mental health law who has schizophrenia. Dr. Saks defies the assumption that a life full of professional success is out of reach for a person with a severe brain disease. In her memoir, she takes readers into the depths of her psychosis and the path she traveled to living a fulfilling life as a respected legal scholar, demonstrating the power of perseverance, the value of therapy and the importance of supportive networks in overcoming the obstacles posed by schizophrenia.

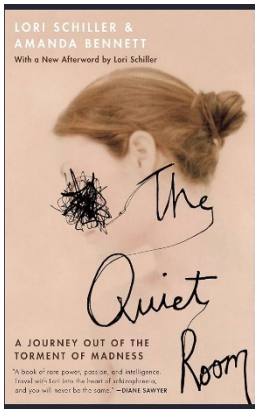


A Beautiful Mind: Mathematical genius John Nash overcame schizophrenia through decades of struggling with psychosis and delusions to later win the Nobel Prize. His accomplishments made possible groundbreaking international applications of game theory. His story has been adapted into a compelling **Academy Award–winning movie** that features key themes such as understanding the human mind’s hidden depths, triumph over adversity and healing through love found in family and community.



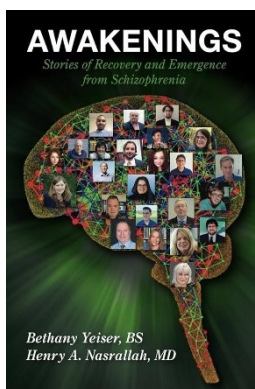
The Collected Schizophrenias: Essays by Esmé Weijun Wang:

Through a collection of astounding personal essays, this book makes a persuasive case for the wide spectrum of lived experiences with schizophrenia, ranging from high-functioning recovery to the chaotic depths of psychosis. The author weaves authentic storytelling with hard facts to illustrate the multifaceted components of her lived experience. Her intriguing essays dive into topics such as the medical community's disagreement with labels, the dangers of institutionalism, building insight into wellness and dispelling long-standing misconceptions.



The Quiet Room: A Journey Out of the Torment of Madness:

A testimony rooted in perseverance and courage, this memoir chronicles Lori Schiller's journey through full-blown schizophrenia while enduring an overwhelming ordeal of repeat hospitalizations, halfway houses, relapses and constant, withering despair. In her detailed personal account, Schiller shares hope through how she survived beyond her shattered world while tapping into the words of the doctors and family members who were by her side throughout the journey.

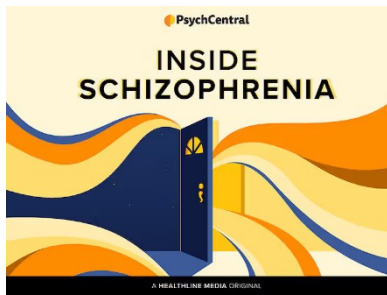


Awakenings: Stories of Recovery and Emergence from Schizophrenia:

Bethany Yeiser, President of the CURESZ Foundation, shares her quest to prove that recovery is possible and sustainable. She tells the stories of 28 people who have recovered and are thriving despite having schizophrenia. These include a law student, a librarian, a musician, a computer programmer, an athlete, a university faculty member, artists, authors, poets and homemakers.

Podcasts/YouTube

Do you want to learn from the recovery stories of countless others who have been through what you've experienced? Look through these podcasts and recommended episodes to start your learning journey about the lived experiences of advocate champions in the schizophrenia and psychosis space.



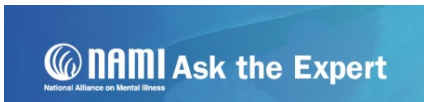
Inside Schizophrenia: This podcast from the website Psych Central provides a deep dive into the personal lives of people living with schizophrenia and the challenges faced by their caregivers. Available on YouTube and across most podcast platforms, Inside Schizophrenia provides invaluable insight through expert professionals as well as those with lived experience. Recommended episodes: **“Grieving the Life You Lost Due to Diagnosis,” “Community Involvement in Recovery”** and **“Accepting a Diagnosis of Schizophrenia.”**



Living Well with Schizophrenia: “Hi, my name is Lauren and I live with schizophrenia/schizoaffective disorder.” This channel shares honest personal testimony of lived experience through well-produced, high-quality educational videos across a variety of topics about recovery. Regular viewers of this channel encounter authentic and compelling insight into wellness while living with schizophrenia-related disorders. A few recommended episodes: **My Experience with Schizophrenia/Schizoaffective Disorder, 10 Signs I'm Slipping into Psychosis** and **How Schizophrenia Starts - My Experience with the Prodromal Phase.**



Unseen and Unheard Podcast and Kody Green YouTube: Kody Green is 28 and has Undifferentiated Schizophrenia. He also is the founder of a non-profit, a motivational speaker and content creator with more than one million followers on TikTok. His podcast episodes and YouTube videos share stories about his struggles and how to navigate through recovery, serious mental health issues and life after incarceration. Hope for Schizophrenia, where the podcast is hosted, also features a variety of tools and worksheets, such as **Preparing for an Episode** and **Supporting Recovery Discussions.**



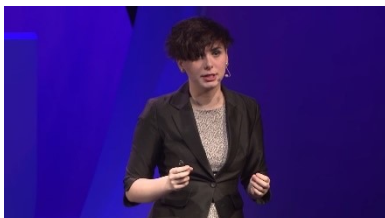
NAMI Ask the Expert Series: Hosted by the National Alliance on Mental Illness' national senior leadership, this series features a variety of topics on the overarching issues of living with a mental health condition, while tapping into the powerful insights of well-respected industry leaders. While it addresses mental illness more broadly, these episodes provide understandings into the bigger picture of mental health in the United States: **People, Place and Purpose: A Vision for the Failing Mental Health System** and **An Evidence-Based Conversation on Violence and Mental Illness**. Another popular episode is **How Employment Supports Mental Health Recovery**.

TED and TEDx Talks

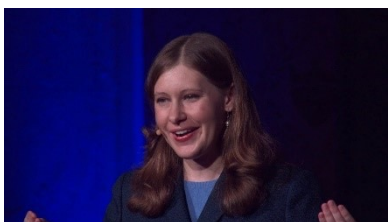
Over the years, accomplished advocates who live with schizophrenia-related disorders have taken the stage at national and regional conferences through TED to share their stories with full transparency. Highlighting their tales of personal resilience, these champions leverage powerful first-hand storytelling to create hope, shape attitudes and dispel stereotypes. These recovery champions are living examples that recovery is possible with schizophrenia-related disorders:



A tale of mental illness -- from the inside | Dr. Elyn Saks | TED. Elyn Saks is a Professor of Psychology, Psychiatry and the Behavioral Sciences at the USC Gould School of Law.



I Am Not A Monster: Schizophrenia | Cecilia McGough | TEDxPSU. Cecilia McGough is a mental health activist, nonprofit executive director, NASA VASTS mentor, keynote speaker, co-author, consultant and former pulsar astronomer.



My journey through schizophrenia and homelessness | Bethany Yeiser | TEDxCincinnati. Bethany Yeiser is the President of the CURESZ Foundation, an author and a dynamic communicator on topics such as the experience of severe, untreated schizophrenia and chronic homelessness.



The voices in my head | Eleanor Longden | TED. Eleanor Longden is a Postdoctoral Service User Research Manager at the Psychosis Research Unit, a joint project between **Greater Manchester West Mental Health NHS Foundation Trust** and **The University of Manchester in England**. She has earned her master's in psychology since the TED Talk appeared.

"The most beautiful people we have known are those who have known defeat, known suffering, known struggle, known loss and have found their way out of the depths. These persons have an appreciation, a sensitivity and an understanding of life that fills them with compassion, gentleness and a deep loving concern. Beautiful people do not just happen." — Elisabeth Kübler-Ross

Additional Online Guides

Recovery is not a one-size-fits-all path, and it's important to explore options that resonate with you personally. The additional resources included here are selected to empower you with knowledge and practical strategies, supporting your ability to make informed decisions about your health and wellbeing.

Embrace these tools at your own pace, and remember, taking small steps consistently can lead to profound changes in your recovery journey.

HealthCentral

Health Central's Living with Schizophrenia guide: This detailed in-depth, expert-written guide taps into insights from lived experience across many categories and common questions: Getting a Diagnosis, What to Expect from Therapy, Accepting Help, Telling Others, Handling Stigma, Taking Medication, Helping Yourself and Getting Accommodations.

Cleveland Clinic

Cleveland Clinic's clinical information on schizophrenia: This guide from the well-respected medical institution addresses essential topics regarding schizophrenia, including Symptoms and Causes, Diagnosis and Tests, Management and Treatment, Prevention, Outlook/Prognosis, Living With Schizophrenia and Additional Common Questions.

National Institute of Mental Health

NIMH schizophrenia articles: This information from the National Institute of Mental Health provides an insightful overview of schizophrenia, detailing its impact on cognition, emotions and social functioning. It highlights symptoms such as hallucinations and delusions, underscores the importance of early diagnosis and discusses current treatment approaches and ongoing research efforts aimed at improving outcomes for people with the disease.

Early Psychosis Intervention

Early Psychosis Intervention's Dealing with Psychosis Toolkit: This comprehensive workbook features insights into two overarching goals for people in recovery: (1) Managing the symptoms of psychosis and (2) Moving forward and enjoying your life. This toolkit can help you learn and build essential skills; you can work through the sections at your own pace.



Strong 365’s Mental Health 101: Psychosis: This provides information about psychosis in teens and young adults, including signs and symptoms, causes and risk factors, screening and diagnosis and coping and recovery. It also details interactive resources and online engagement opportunities beyond those covered within the toolkit.



Wellness Recovery Action Plan (WRAP): Developing a Wellness Recovery Action Plan for schizophrenia involves identifying personal triggers and early warning signs, devising effective coping strategies such as mindfulness or creative activities and establishing a supportive network of family, friends and/or groups. Regular review and adjustments ensure the WRAP remains relevant and effective in helping you manage symptoms and promote overall wellbeing.



Mental Illness Recovery - Clubhouse International: This global nonprofit organization is dedicated to supporting people who live with mental illness through a unique community-based model known as the Clubhouse Model. Its mission focuses on empowering members by providing opportunities for employment, education and social inclusion within a supportive environment. Clubhouses offer a place where you can regain your confidence, skills and sense of belonging, fostering recovery and personal growth.



Seeking Supported Employment: What You Need to Know Workbook: This tool is designed to explain supported employment programs and guide your decisions about finding and keeping a job while living with a mental illness. It provides guidelines for finding purposeful, engaging work as you manage your recovery journey.



SOAR Works! (SAMHSA): The SOAR (SSI/SSDI Outreach, Access and Recovery) website is a resource hub dedicated to enhancing access to Social Security Disability benefits if you are experiencing (or are at risk of) homelessness and have a mental illness. SOAR equips communities and individuals with training, tools and technical assistance to effectively navigate the disability application process.



Treatment Advocacy Center: This organization offers comprehensive information and resources dedicated to advancing policies and practices related to mental illness treatment. It focuses particularly on issues surrounding severe mental illnesses such as schizophrenia. TAC advocates for improving access to care, legal reforms for involuntary treatment when needed and early intervention strategies to enhance outcomes for those living with severe mental illness.

Free mental health training

Many resources are available that offer support, guidance and practical strategies to help you manage your mental health. While the following list includes mental health training that is not specifically tailored to schizophrenia, the resources offer valuable insights and skills that can be useful.



CURESZ Foundation: The CureSZ Foundation offers free training and resources aimed at educating individuals, caregivers, healthcare professionals and the public about effective management and support strategies.

“If you’re going through hell, keep going.” —Winston Churchill



NAMI Peer-to-Peer Courses: This free, eight-session educational program is for adults with mental illnesses who want to better understand themselves and their recovery. This is a place to learn more about recovery in an accepting environment, as well as encounter compassion and understanding from people who relate to your experiences.



Mental Health America on Psychosis: The Mental Health America (MHA) screening page on psychosis is for people who are concerned about symptoms of psychosis. It offers a confidential, online screening tool designed to assess potential symptoms of psychosis, such as hallucinations, delusions and disorganized thinking. By guiding users through a series of questions, the screening aims to help you better understand your experiences and provides information on next steps, including seeking professional help if needed.



Adult or Youth Mental Health First Aid: In this course, you learn risk factors and warning signs for mental illness and addiction concerns, strategies to help someone in both crisis and non-crisis situations and where to turn for help. Local nonprofit organizations will often have grant funding to provide this training for free in their communities; you can start with those organizations to get connected with a training opportunity.



Copeland Center for Wellness and Recovery: The Copeland Center offers evidence-based and experiential-based peer-to-peer learning opportunities in person and online. The training is created and co-facilitated by experts with lived experience who help build recovery on the values of hope, self-determination, self-advocacy and building support. Trainings include “Taking Action for Whole Health and Wellbeing” and “Peer Supported Community Inclusion.”

**Shattering barriers to treatment,
survival and recovery for people
with schizophrenia and other
psychosis spectrum disorders.**

Schizophrenia & Psychosis Action Alliance
2308 Mount Vernon Avenue, Suite 207
Alexandria, VA 22301-1328
240-423-9432
sczaction.org

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