



Schizophrenia[®]
& Psychosis
Action Alliance

Caregiver Toolkit

Introduction

As a caregiver to someone with schizophrenia or other psychosis spectrum disorder, you give so much of yourself to help ensure your loved one is cared for and safe.

Our Caregiver Toolkit can help you navigate the complex landscape of this serious brain disease and provide support for family members, loved ones and professionals caring for those with schizophrenia.

In this toolkit, you'll find:

- Books and podcasts where you can learn more about the disease and hear about other caregivers' experiences.
- Treatment information.
- Links to support groups.
- Questions to ask healthcare providers.
- Tips on how to talk with your loved one about their wellbeing and needs.
- Templates for keeping important contact information, a list of your loved one's medications and their brief medical history at your fingertips.

Caregivers are incredibly powerful and valuable members of our schizophrenia community. **You** and your loved ones are the reason we work to advance transformative systemic change so that people with schizophrenia can thrive.

About Schizophrenia: The Basics



What does a diagnosis of schizophrenia really mean?

Schizophrenia is a complex spectrum of serious brain diseases that affect a person's perception of reality. It can involve experiences such as:

- **Hallucinations:** These can occur in any of the five senses (sight, hearing, touch, smell or taste), but most frequently involve hearing voices and seeing things that are not there.
- **Delusions:** These are strong beliefs that are not based in reality, such as thinking one has superpowers or is under the control of unseen forces.
- **Challenges to thinking clearly:** This includes difficulty organizing thoughts, making decisions and/or expressing oneself clearly.

These symptoms can make it challenging to engage in daily activities (such as maintaining personal hygiene), manage finances, take medications, participate in school or work and engage in social interactions.

What causes schizophrenia?

We are still trying to understand all of the causes. Variations in our genes are thought to contribute to the risk of developing schizophrenia. Genetic changes interact with environmental factors – such as exposure to infections before birth or severe stress during childhood or adolescence – to increase the risk. S&PAA is involved in several ongoing national research projects that are seeking more insights into what causes the disease.

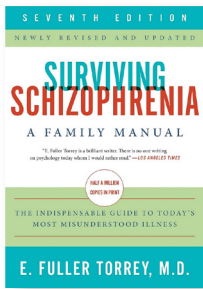
How common is the disease?

Schizophrenia and related psychosis disorders affect at least 1 in 100 people in the United States – or 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 my loved one ever recover?

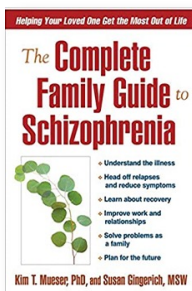
People with schizophrenia typically require lifelong treatment to manage their symptoms, and finding the treatment that works best for each person can be challenging and take time. However, with proper treatment and support, people with schizophrenia can thrive. It is important to find a treatment team your loved one trusts who can work with all of you to guide the treatment journey.

Educational Resources



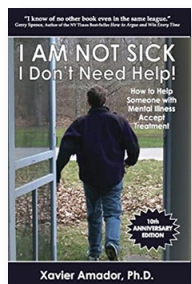
Surviving Schizophrenia, 7th Edition

This book, written by a prominent psychiatrist and schizophrenia researcher, is a comprehensive and empathetic guide for people living with schizophrenia, those who love them and healthcare providers. It details the causes, symptoms and treatments of schizophrenia and combines scientific research with clinical and practical advice. This book also addresses the societal aspects of schizophrenia, advocating for improved policies and better resources for those impacted by the condition.



The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life

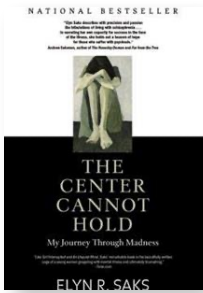
This book is written by an expert clinical psychologist and social worker, both of whom have extensive experience treating schizophrenia. It delves into strategies to improve the quality of life for those with schizophrenia, covering topics that range from treatment options to advocacy. It emphasizes the importance of understanding the condition, navigating the healthcare system and fostering an environment that promotes the well-being and autonomy of the person with schizophrenia. This book focuses on hands-on, practical daily living and coping strategies for family members.



I'm Not Sick – I Don't Need Help!

This book addresses how to communicate with your loved one who has schizophrenia – especially when they have a symptom called anosognosia, in which they do not believe they have an illness and consequently refuse treatment. It is written by Dr. Xavier Amador, a clinical psychologist with extensive experience in schizophrenia whose brother had this condition. This book offers practical strategies based on an approach called LEAP (Listen–Empathize–Agree–Partner). The principles of LEAP focus on reflective listening and empathy, aimed at building trust and understanding rather than confronting or arguing with your loved one.

Educational Resources



The Center Cannot Hold – My Journey Through Madness

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.



Schizophrenia: Three Moms in the Trenches

This podcast, available on YouTube and on multiple podcast platforms, is hosted by mothers who discuss their daily challenges and triumphs in caring for children with schizophrenia.



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. It's available on YouTube and on multiple podcast platforms.

Treating Schizophrenia

With proper treatment, people with schizophrenia can recover and thrive. The earlier treatment begins, the better it is for long-term outcomes. However, treatment at any point can make a meaningful and significant difference in your loved one's life. Treatment should be a dynamic and ongoing journey, as your loved one's needs will likely change over time.

Effective treatment for schizophrenia includes medication, psychological therapy and supportive services such as employment and education support. An ideal treatment program will involve all three of these types of interventions. For those in their first few years of having schizophrenia, coordinated specialty care clinics are excellent for providing best-practice comprehensive services.

Medication

Medication, and specifically antipsychotic medication, is typically the first treatment a healthcare provider will prescribe for schizophrenia. Many antipsychotic medications are available, and they may differ in how they are given (some may be a daily oral pill, while others may be given as an injection that can last for several months). It can take time to find the medication and dose that works for your loved one.

There are two broad types of antipsychotic medications:

- **First-generation or “typical” antipsychotic medications.** These older medicines can have more severe side effects, including intense muscle stiffness or a condition called tardive dyskinesia, which causes involuntary muscle spasms. However, some people experience more improvement in their symptoms with these treatments compared with the second-generation antipsychotic medicines.
- **Second-generation or “atypical” antipsychotic medications.** These medicines are more common today because they have fewer side effects. However, many of the medicines in the second-generation family still can cause side effects, including weight gain and increased cholesterol and blood-sugar levels.

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

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

Psychological therapy

Both individual and group therapy are considered vital ongoing treatments for those with schizophrenia and their loved ones. They are crucial for “re-entering” community life after the disruption that schizophrenia often causes. 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.
- 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 therapy include:

- **Cognitive behavioral therapy (CBT) for psychosis:** A structured therapy that helps people with psychotic disorders challenge and modify their distorted thought patterns and beliefs to reduce distress and improve functioning.
- **Cognitive remediation:** A therapeutic approach that aims to enhance cognitive skills such as memory, attention and problem-solving.
- **Family psychoeducation:** Educating and providing support to families to help them better understand and cope with their loved one's brain disease.
- **Illness self-management training:** Equips people with self-management skills and strategies to cope with their symptoms and improve their overall well-being.
- **Social skills training:** Focuses on enhancing interpersonal and social functioning, helping people develop effective communication and relationship skills.

Supportive Services

People with schizophrenia also can benefit from support for their daily needs:

- **Supported education and employment** programs help people with schizophrenia pursue educational and employment goals, providing hands-on, practical support with each step of the process. For best-practice approaches, the only requirement for participation is that the person has a desire to return to school or work.

- **Peer Support** services are delivered by people with lived experience of schizophrenia who are further along in their recovery journey. Peer support specialists provide support, empathy and guidance to others facing similar challenges.
- **Supported Housing** initiatives help people find stable housing according to their level of need.

For more details about these therapies, visit <https://sczaction.org/treatment/>.

Barriers to treatment

About half of people with schizophrenia do not take their prescribed medications as directed. The most common reason is anosognosia, a neurological symptom in which people are unaware they have the disease. An estimated 57% to 98% of people living with schizophrenia experience anosognosia.

Anosognosia can be deeply frustrating, as it often causes your loved one to refuse to take their medicines – which can lead to severe episodes of psychosis and the trauma to both patients and families that accompanies these episodes. In addition, many people have never heard of this cruel symptom, so they may misinterpret your loved one's behavior, omit it from your loved one's diagnosis and/or fail to treat it as part of the overall disease.

LEAP (Listen-Empathize-Agree-Partner) training is one way to help caregivers use evidence-based communications to create relationships with their loved ones that can lead to treatment. LEAP training is provided through the Henry Amador Center on Anosognosia; for more information, visit <https://hacenter.org/online-trainings>.

Schizophrenia Support Groups & Helpline

S&PAA manages many support groups for people with schizophrenia and their care partners, as well as a helpline (phone and email) for navigating the many aspects of schizophrenia.

Helpline

We offer a free information helpline with specially trained team members who can provide personalized information and resources to people with schizophrenia-related diseases and their families/caregivers. Our helpline can answer your questions, connect you with tools and resources and help you find support services in your community.

We are not a direct service provider, so we can't make appointments or direct referrals. However, our team can provide you with support, encouragement and assistance throughout your journey.

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



We operate a toll-free phone helpline
Monday-Friday from 9 am to 5 pm
in all time zones:
1-800-493-2094.

You also can reach the helpline via email at
info@sczaction.org

Support Groups

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.

For specific days/times of FFC meetings (including virtual meetings) and to register, visit <https://sczaction.org/find-a-peer-support-group/>.

Schizophrenia Alliance (SA)

Schizophrenia Alliance is a self-help group for people living with schizophrenia or a related disease. It was founded in 1985. Today, thousands of people participate in weekly meetings in the United States and around the world. Those who have not been officially diagnosed with schizophrenia but have experienced psychosis also are eligible to participate.



Visit
<https://sczaction.org/peer-support-groups/>
for more information.

For specific days/times of SA meetings
(including virtual meetings) and
to register, visit
<https://sczaction.org/find-a-peer-support-group/>



Talking with Healthcare Providers: Questions to Ask

These questions can help you better understand your loved one's diagnosis and treatment and learn about other support that may be available.



1. What specific schizophrenia symptoms have you observed in my loved one?

- a. What tests have you conducted to rule out other potential diagnoses?

2. What are the specific treatment goals for my loved one?

- a. How will progress be measured?
- b. How will the treatment plan be tailored to my loved one's needs and preferences?

3. How did you select this medication for my loved one?

- a. What are the most common side effects? Are there other treatments that can address these side effects?
- b. Are there other ways to take this medicine (such as a long-acting injectable vs. an oral pill)? Do you suggest one over another, and why?
- c. What types of check-ups should we get (and how often) to monitor the medicine's effectiveness?

Talking with Healthcare Providers: Questions to Ask



4. What are all of the treatment options available at this clinic/treatment center?

- a. Are there other community resources that provide additional support?
- b. If so, which ones would you suggest, and why?

5. What are your crisis management resources?

6. If my loved one's symptoms worsen suddenly, what should I do?

7. What support do you provide if my loved one is involuntarily hospitalized?

8. What support do you provide for family members? How about siblings?

Talking with your Loved One: Questions to Ask



Communicating with a loved one affected by schizophrenia can be a challenging journey. It's crucial to engage with your loved one from a place of empathy, actively striving to understand their viewpoint without judgment, regardless of whether their perspective aligns with yours. This approach supports understanding and reinforces trust and respect, which increases the likelihood that you can make decisions together to improve their quality of life.

Emotional wellbeing

1. How are you feeling today?
2. Is there anything specific that's bothering you or causing distress right now?
3. Are you experiencing any symptoms or thoughts that are troubling you?
4. How can I best support you today?
5. Can you tell me more about what your mood has been like recently?
6. Have you noticed any changes in your thoughts or feelings this week?

Treatment and medication management

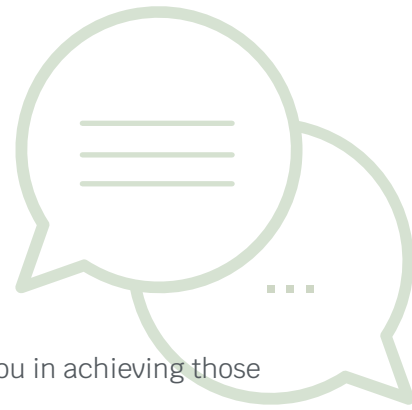
1. Have you taken your medication as it was prescribed?
2. Do you have any questions or concerns about your condition or treatment plan?
3. Are you experiencing any side effects from your medication?
4. Is there anything we need to discuss with your doctor at your next appointment?

Daily living and comfort

1. How can we make your living environment more comfortable for you?
2. Are you interested in any activities or hobbies today?
3. Would you like some company, or would you prefer some time alone right now?
4. What part of your daily routine do you enjoy the most?
5. Are there any tasks or chores that are becoming difficult for you?

Social engagement and support

1. Have you talked to your therapist (or other mental health professional) recently?
2. How can we work together to manage your stress and reduce triggers?
3. Would you like to involve other family members or friends in your support network?
4. Who in your life has been the most supportive recently?
5. Are there any social situations you're feeling anxious about?



Future planning and goals

1. What would you like to accomplish in the next few months? How can I support you in achieving those goals?
2. How do you feel about your progress in your personal goals?
3. Are there any concerns or worries you have about your future?
4. How can we plan for potential challenges or crises in advance?

Personal strengths and health routine

1. How can we maintain a healthy routine together, including healthy eating, exercising and getting a good sleep?
2. What do you feel are your strengths and talents, and how can we nurture them?
3. What new healthy habits would you like to develop?
4. What skills or hobbies make you feel most fulfilled?

Open dialogue

1. Is there anything else you'd like to talk about or share with me today?
2. What has brought you joy or comfort this week?
3. Are there any recent experiences or feelings you'd like to discuss further?



Important Contact Information

	NAME	PHONE NUMBER	EMAIL
Psychiatrist			
Therapist			
Social Worker			
Primary-Care Physician			
Pharmacy			
Hospital Emergency Dept			
Neighbors (e.g., for pet- or child-care help if needed)			

Medication List

(Note: Include over-the-counter medicines such as vitamins and allergy remedies)

NAME OF MEDICATION	DOSAGE (HOW MUCH/HOW OFTEN)	REASON
1.		
2.		
3.		
4.		
5.		
6.		
7.		•
8.		
9.		
10.		

Brief Medical History of your Loved One's Schizophrenia

Diagnosis	When was it diagnosed?
Key symptoms	Current treatment(s)
Is current treatment effective?	Side effects from treatment(s)
Frequency of psychosis episodes	What are your loved one's treatment goals?

Brief Medical History of your Loved One's Schizophrenia

Strengths and interests of your loved one

Suggestions for how to communicate/interact with your loved one

Navigating Healthcare Laws: Important Options

HIPAA Waiver of Authorization

A HIPAA Waiver of Authorization is a legal document that allows a person's health information to be used or disclosed to a third party. The waiver is part of a series of patient-privacy measures included in the Health Insurance Portability and Accountability Act (HIPAA) of 1996. (Learn more about HIPAA here: <https://www.investopedia.com/terms/h/hipaa.asp>)

Patient information covered under HIPAA – called “protected health information” – is information that can be linked to a specific person and is held by a health insurer, healthcare provider or healthcare clearinghouse. It's important to have your loved one sign a HIPAA waiver when they are as healthy as possible. During periods of crisis, your loved one may refuse to allow sharing of information with you or other family members – especially if they are being cared for involuntarily. A HIPAA waiver will allow you access to their health information even in these instances."

If you don't have a signed waiver at the time of a crisis, HIPAA does allow you to communicate helpful information to doctors and other clinicians about your loved one's symptoms and recent events.

Advance Medical Directive

An Advance Medical Directive is a legal document that provides medical direction for someone who may be unable to make medical decisions for themselves. It can cover anything from who can ride in an ambulance to what medicines a doctor can prescribe.

To complete an advance directive, download a form through your state's Health and Human Services department when your loved one is as healthy as possible. Keep it with your other important documents and provide a copy to your loved one's healthcare provider(s) to be included in their medical record.

Guardianship

A legal guardian is someone appointed by a court to make decisions about personal and property interests of another person who is deemed incompetent to make these decisions on their own. For example, a guardian can be given the authority to make decisions about another person's medical care.

If you think seeking guardianship of your loved one may be necessary, consult a disability or mental health attorney. The legal filings are different in each state. Guardianship can cost money and time, so prepare for this by gathering documentation before a crisis that supports your case for guardianship. If your loved one is able, discuss the possibility of guardianship with them and share ways this can help protect them both medically and financially.

What to Do in a Crisis

Your goal during a schizophrenia-related emergency is to stabilize the situation and get your loved one professional help as quickly as possible. Below are some general guidelines for handling a crisis such as an episode of psychosis.

Who to call

- Don't try to manage the situation alone. Having another person present or on the phone with your loved one can help defuse the situation.
- Start at the top of your Important Contact Information list and work your way down. If it is an evening or weekend and you cannot reach providers or agencies, call the most appropriate hotline.



How to talk with your loved one

- **Speak to your loved one in a calm, quiet voice.** If it seems they aren't listening or can't hear you, it's possible they are experiencing auditory hallucinations ("voices"). Don't shout, as raising your voice may escalate tension.
- **Keep instructions and explanations simple and clear.**
 - o THIS: "We're going to the car now."
 - o NOT THIS: "After we get in the car, we'll drive to your doctor's office so they can examine you."
- **Respond to delusions by validating your loved one's feelings,** not downplaying them.
 - o THIS: "This must be frightening."
 - o NOT THIS: "You shouldn't be frightened. Nobody's going to hurt you."
- **Avoid direct eye contact,** as it may be perceived as confrontational or threatening.
- **Avoid physical touch,** as it may be perceived as a threat and trigger a violent reaction.
 - o If necessary, ask for permission before touching them.
- **Don't stand over your loved one.** If they are seated, seat yourself to avoid being perceived as trying to control or intimidate.
- **Don't give multiple choices or ask multi-part questions,** as this can increase confusion.
 - o THIS: "Would you like me to call your psychiatrist?"
 - o NOT THIS: "Would you rather I call your psychiatrist or your therapist?"
- **Don't threaten or criticize.** Acute brain illness is a medical emergency. Suggesting that the person has chosen to be in this condition won't help and may escalate tension.
- **Don't argue with others on the scene.** Conduct all discussion of the situation with third parties quietly and out of the patient's earshot.

Advancing system change and promoting recovery through Research, Advocacy, Education & Care for the millions of people who live 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

Copyright © 2023, Schizophrenia and Related Disorders Alliance of America DBA Schizophrenia & Psychosis Action Alliance (S&PAA). All Rights Reserved



Schizophrenia[®]
& Psychosis
Action Alliance