

## FAQ

**Q: My loved one was diagnosed with SMI, and I am overwhelmed. Where do I start?**

A: Begin with yourself. You will need to adjust your expectations for your loved one and yourself. Recognize that their illness impacts perception, interpersonal interactions, and decision making. You will need new strategies for communicating and collaborating. Recognize that your patience will be tested, and pace yourself for a long journey. TAC provides [multimedia resources](#) to help you learn and materials related to [ambiguous loss](#) to help you cope with grief.

**Q: What are common terms I need to know?**

A: Following are basic definitions for key words and acronyms related to SMI, listed alphabetically and linked to resources for further information:

**ACT**: assertive community treatment, a model for intensive outpatient treatment served by a multi-disciplinary team.

**Adjudication**: the formal, legal process for determining whether a crime was committed and what penalties the accused might face. A person with SMI who is too symptomatic to understand the [criminal legal](#) process cannot be adjudicated for an alleged crime unless their “competency” is restored (see below).

**Anosognosia**: a symptom of illness that disables a person’s insight into their condition.

**Ambiguous loss**: a loss that lacks clarity or resolution, such as when someone is “gone but not gone” due to psychiatric deterioration.

**AOT**: assisted outpatient treatment, court-ordered outpatient services.

**CCBHC**: certified community behavioral health center, a model for community-based outpatient care within a hub. Search [thenationalcouncil.org](#) for state-by-state listings.

**CIT:** crisis intervention teams training for law enforcement. When calling 911 for a mental health emergency, request response from CIT-trained officers. Call 988 instead of 911 if the mental health emergency does not include a threat of violence (see below).

**Commitment:** an involuntary hospitalization for a psychiatric condition, with criteria established by state laws.

**Competency:** fitness for trial, meaning someone is found mentally well enough to participate in a criminal legal process. A person found to lack competency cannot be “adjudicated” (see above) for an alleged crime until competency is restored, often with medication while in a state hospital bed.

**Continuum of care:** a range of inpatient and outpatient options for psychiatric treatment.

**Coordinated specialty care:** a model for [early intervention programs](#) to treat illnesses that include psychosis. SAMHSA provides an [Early Serious Mental Illness Treatment Locator](#).

**Emergency evaluation:** the first step toward an [involuntary hospitalization/commitment](#), with state laws that govern the process and how it can be initiated.

**Forensic services:** mental health services provided as part of a criminal legal process, such as competency restoration or for someone found not guilty by reason of insanity (NGRI) or, in some states, guilty except for insanity (GEI).

**HIPAA:** Health Insurance Portability and Accountability Act, federal law that protects health information and patient records and requires providers to keep medical information confidential unless sharing for reasons of safety or continuity of care or with permission granted through a signed release of information (ROI), power of attorney, or guardianship.

**Mental health history:** a document to maintain and share with anyone making decisions about a person’s treatment.

**MI:** motivational interviewing, a strategy for communicating with someone who lacks insight into their condition. [LEAP](#), developed by Dr. Xavier Amador, is a specific MI method.

**988:** The nationwide phone number to call for the [Suicide & Crisis Lifeline](#). TAC provides a resource to help families plan for SMI [emergencies](#).

**Psychosis:** a collection of symptoms indicating a mental break from reality.

**SAMHSA:** Substance Abuse and Mental Health Services Administration, federal agency

responsible for grants and guidance, with a treatment locator based on an address in any state: [findtreatment.gov](http://findtreatment.gov). For services in Spanish, visit [EncuentraApoyo.gov](http://EncuentraApoyo.gov).

**SMI:** severe mental illness, comprising conditions along the schizophrenia spectrum and the most severe forms of bipolar disorder and depression.

**SSDI/SSI:** Social Security Disability Insurance/Supplemental Security Income, federal benefits that are based on disability and work history. A documented SMI will generally make someone eligible for either of these benefits but filing takes time and organization.

### **Q: Does TAC provide a way for families to support one another?**

A: TAC provides an online place for solidarity and idea sharing, which can be found by searching TAC Family Support Group on Facebook. Please be advised this is a private group for family members. Agree to the group guideline questions to be added to the group.

### **Q: Where do I start when it comes to SMI outpatient treatment options?**

A: Pathways to treatment may be voluntary or involuntary. TAC provides an article about the [continuum of care](#) with basic vocabulary for understanding what to look for.

- If there is a certified community behavioral health center (CCBHC) in your area, you might start there. The National Council lists [CCBHC options by state](#).
- Treatment locator from the [Substance Abuse and Mental Health Services Administration \(SAMHSA\)](#).
- Look up your state on [TAC's interactive map](#), then click to find SMI resources in your state.
- Addiction support, listed by state: [Free Rehab Centers](#).
- Seek help from an insurance agent and/or request case management. Persist if an initial list of providers comes up short: [Challenges with insurance](#) and accountability for parity are ongoing.
- TAC provides a place to begin researching if there may be assisted outpatient treatment ([AOT](#)) for involuntary outpatient care in the county of residence.

### **Q: If my loved one's treatment provider won't talk with me, what can I do?**

A: Learn about [HIPAA](#) and know what you can share and ask within the boundaries of confidentiality laws. Regardless of whether your loved signs a release of information (ROI), you can share [mental health history](#). You are not bound by HIPAA, which applies to professional providers.

HIPAA allows for basic information sharing when it's in the best interest of the patient, especially when there are safety concerns. You can let the provider know you've researched HIPAA law and that you respect their need to protect sensitive information.

You can ask providers for general information, especially if you provide essential support. Here's a possible way to ask: "I understand that you cannot share a patient record without an ROI, but I'm not asking for that. Can you please provide general guidance about how to support someone with a diagnosis of [schizophrenia, bipolar disorder, psychosis, suicidal ideation...] at home? Are there general things I need to know for the safety and well-being of everyone in our home?"

### **Q: Someone with SMI is in jail instead of a hospital. Now what?**

A: While your loved one is incarcerated, plan to share [mental health history](#) with providers responsible for care in the jail (often a contracting agency). You might look at the jail's website to see what messaging they post related to mental healthcare for inmates. Sometimes it helps to point out what services are promised. Research [complaint options](#) if there is evidence of abuse and/or neglect.

A person who has been arrested and incarcerated may be moved from jail to a treatment facility or back into the community for various reasons.

#### **Here are a few scenarios:**

- Their defense attorney might question whether they are well enough to act in their own defense. Court-ordered "**competency restoration**" may include medication and court training done in a state hospital or somewhere else. TAC provides an [article](#) with information and sample questions for families to ask attorneys.
- If the person is found competent but the case is linked to poor treatment adherence and/or substance abuse, the case might be adjudicated through a mental health or drug court, if that option exists and the person qualifies.
- Charges may be dropped to enable diversion into treatment, which might be either voluntary or involuntary, depending on the programs available. A new option is dismissal upon civil commitment to assisted outpatient treatment (AOT), which is a protocol promoted with an [article and video](#) from TAC's AOT Implementation Team.
- If the person is bailed out, they could be evaluated and determined to meet criteria for civil commitment under their state's law. TAC provides [state-by-state information](#) about treatment laws.

### **Q: What is the difference between bipolar and schizoaffective disorder?**

A: Bipolar disorder affects a person's ability to self-regulate their mood. [Psychosis](#) can be a secondary symptom of mania or depression, with these other possible symptoms that might

co-occur during a mood swing: anxiety, irritation, focus problems, and suicidality. A person with bipolar disorder will experience periods of stability (however brief) between mood episodes.

Schizoaffective is an illness where a person has a mood disorder diagnosis and a separate psychotic disorder diagnosis. The term “affective” refers to mood. Psychosis, paranoia, cognitive deficits, and other common features of schizophrenia may occur without the presence of mania or depression.

An accurate diagnosis is important for treatment planning. For example, lifestyle and behavioral changes that might work with bipolar disorder may not support schizoaffective disorder to the same benefit. Author and Mental Health Coach Julie A. Fast offers more in a [bphope](#) article. Refer also to TAC’s resource about severe mental illness ([SMI](#)).

### **Q: How do I help my loved one with SMI find housing?**

A: People with complex medical needs related to SMI may need supportive as well as affordable housing. Many areas of the country lack sufficient options for this population. [SAMHSA’s PATH program](#) is a place to begin; for local information search the internet by spelling out Projects for Assistance in Transition from Homelessness and your state and/or city name. A TAC article provides additional information and resources related to [housing](#).

### **Q: My loved one with SMI is missing. What do I do?**

A: File a missing person report with law enforcement as soon as you know your loved one is missing. A waiting period is not required, despite common misinformation. Having this report on file will allow officers to know about the mental illness and that someone cares for the person if they turn up. TAC provides an [article](#) with more information.

### **Q: What can I do if my loved one with SMI feels “cured” and wants to stop taking medication?**

A: SMI is chronic, and the symptoms are often cyclical, like high blood pressure or diabetes. People with those types of conditions or SMI often get better and stay better because of medication. If they stop, they may become unstable. If side effects cause problems or the medication is not meeting the client’s needs, the prescriber is responsible to collaborate and adjust medications or jointly make the decision to discontinue. This can be a very sensitive topic, and [communication](#) with your loved one is key.

Understanding best-practice treatment protocols can also be helpful: TAC provides an article about [psychosis](#) that is a place to begin and [multimedia resources](#) for deeper learning.

## **Q: My loved one in psychosis is barricaded inside the home. What now?**

A: Call 988 if there are no immediate signs of violence. Request a mobile crisis team with authority to issue a hold to have someone taken to the hospital. If your local 988 line does not provide crisis response, you can look up a mobile crisis team in your area and call them directly. One place to research mobile options in your area is to check [The Right Response Directory | Alternative to Police Response](#).

Call 911 if there are weapons or evidence of violence in the moment. Ask for responders with crisis intervention training and explain your loved one's diagnosis and symptoms. TAC provides more information about [emergencies](#), including what to do if you don't live in the same area as your loved one. Whether law enforcement or crisis responders will enter a home uninvited creates a complicated situation for families.

### **Here are a few considerations:**

- Have [mental health history](#) written and printed to ensure that anyone assessing a person has more than a snapshot-in-time of their condition.
- Know your [state's treatment laws](#) so that you understand what is required for an emergency evaluation, which is what happens when law enforcement and/or providers issue an initial hold to have someone transported to an inpatient facility for further evaluation and treatment.
- Prepare to use language from the state criteria (such as grave disability, imminently threatening harm, etc.), when truthfully explaining the symptoms and behaviors.
- Prepare to discuss how similar behaviors in the past may have led to harm.
- Consider whether a team that includes providers and law enforcement might have more influence on whether your loved one might open the door.
- If one team leaves without access to your loved one, plan to call again—and again. You are creating a record of the crisis, and not all responders will approach the situation the same way.

## **Q: What are the risks for suicide and/or violence against our family if our loved one with SMI continues to experience untreated psychosis?**

A: Risks for harm are higher when a person experiences untreated psychosis. Family members need to consider the possibilities for violence and develop safety plans. TAC provides an [article](#) with information about suicide, threats of homicide, considerations for an order of protection, and basic strategies to make a home safer. Learning about red flag laws in your state and gun safety can also be important if a loved one with untreated SMI may become violent. Families must not take their own self-protection lightly and cannot be

expected to endure harm and violence in order for a loved one to be eligible for care.

**Q: I'm worried about losing my job because I need to care for my loved one with SMI. What options do I have?**

A: Taking time off during a crisis may not be possible for everyone. If some down time is possible, consider how self-care may help you cope with the stress of being a caregiver or supporter for a person with SMI.

**Here are a couple of practical tips that may help:**

- The [Family and Medical Leave Act](#) (FMLA) allows workers to take time off to care for a loved one, without fear of losing their jobs. Providing needed care to a family member with SMI is a qualifying reason for FMLA leave.
- To maintain your own stability, practice self-care. Many employers offer an employee assistance program (EAP) that includes confidential counseling. The U.S. Department of Health and Human Services provides [general information about EAPs](#).

**Q: What information is important to keep track of for my loved one?**

A: A concise [mental health history](#) is a critical tool for communicating with providers and might help a person with SMI meet criteria for hospitalization, outpatient services, housing assistance, benefits, or something else. Do your best to maintain a running timeline of hospitalizations, medications, key symptoms, encounters with law enforcement, and anything else that tells the story of the illness. Keep this information in multiple locations, on paper and digitally, so it can be shared promptly when a new situation emerges.

Consider including photos. Seeing a photo of someone “at baseline” (when things are going well) can help a first responder understand how a person has psychiatrically deteriorated. Additionally, care partners can track current medications and those that have been helpful or unhelpful in the past. TAC provides a downloadable medication log within a resource about [medication management](#). The mental health history and medication log can be shared together.

**Q: Why do I feel like my loved one is gone, even though they are still alive?**

A: What you are experiencing is a normal and complicated grief caused by [ambiguous loss](#). Your loved one with SMI is here and not here (as you know them) at the same time. The person who is ill may also feel grief as they experience ambiguous loss related to their health and opportunities. TAC staff offer periodic seminars for groups of individuals who want to explore coping strategies for managing an ambiguous loss related to SMI. To be added to the interest list, email [jclark@tac.org](mailto:jclark@tac.org).

## **Q: How do I prepare for a holiday with SMI in my family?**

A: Pause to accept that roles, rules, and rituals are changed by SMI. Then consider what is still possible and what can be adapted.

Here are prompts for self-reflection:

- Do you take responsibility for other people's behaviors and choices? What do you need to let others own?
- Are there traditions or "rules" that don't work or cause stress? Which ones can go?
- Can you suggest a new ritual for honoring the holiday and the people you love? Is it better to connect in public, outdoors, or apart? Could you connect by thinking of someone and lighting a candle or planting a painted rock in their honor?
- Give yourself grace and prioritize what you need to foster a sense of well-being. This is hard because it's hard, not because you've made a mistake.

## **Q: Does marijuana-use increase a person's risk for a psychotic disorder?**

A: [Research](#) supports an association between heavy marijuana use and an increased risk for psychosis and schizophrenia among adolescents. Here are additional sources for information:

- TAC provides an [evidence brief](#) about the association between substance use and SMI.
- An advocacy organization called Johnny's Ambassadors provides a [summary of research articles](#) about the impacts of marijuana on mental illness in adolescents.
- TAC provides an [article](#) about co-occurring SMI and substance use disorder (SUD) and treatments.

## **Q: What might a stranger do when encountering a person in public having an obvious mental health emergency?**

A: The goal is medical care, not criminalization. With that in mind, calling local law enforcement at a non-emergency number might be a place to start. Ask if they have a mental health or community response option. Explain that you are concerned about the person's well-being. Be sure to provide a description of the person and their exact location. If that doesn't work, or if you want to research alternatives for crisis outreach on your own, try searching online:

- To find cities with community responder programs, search on the website for [Law Enforcement Action Partnership](#).
- To seek a mobile crisis program, check the [Right Response Directory](#).

*If there is an imminent risk for violence or harm, call 911 and ask for responders with CIT training. Always prioritize your own safety first. If the person in distress is coherent and wants help, you can remind them that calling 988 is an option for 24/7 emotional support.*

TAC's resource about [emergency planning](#) provides additional information.