Guide for

SMI Caregivers in Crisis: What You Need to Know

But No One Ever Tells You

A National Shattering Silence Coalition publication

SMI CAREGIVERS IN CRISIS

WHAT YOU NEED TO KNOW BUT NO ONE EVER TELLS YOU

INTRODUCTION

The National Shattering Silence Coalition developed this guide in response to the many families who have reached out and needed help during times of crisis. It was written to help caregivers navigate what can be a difficult and lonely journey when caring for a loved one living with a serious mental illness / serious brain disorder. We hope that this guide offers you the support needed to improve outcomes for your loved ones battling serious mental illness (SMI) in a system that is often stacked against them.

**The National Shattering Silence Coalition is not liable or responsible for any information provided in this guide. This guide is not intended to provide legal advice and is for informational purposes only.*

HIPAA FOR LOVED ONES

How can I share important information about my loved one with the treatment team?

Many people don't realize that HIPAA does not prevent you from communicating with your loved one's medical team. Healthcare providers are NOT required to disclose this communication to the individual receiving treatment. If your loved one is hospitalized, call and ask to speak to someone on the treatment team, informing them that you have vital information regarding the patient's history that is important in caring for your loved one. Providing a medical history is invaluable in creating a treatment plan that will best address their immediate needs, including those of safety.

If you want this information to be provided in confidentiality, it is important to communicate this to providers. Federal law 45CFR 164.524(a)(2)(v) protects providers from having to share the information with your loved one.

This law states "An individual's access to [to protected health information] may be denied if the protected health information was obtained from someone other than a health care provider under a promise of confidentiality and the access requested would be reasonably likely to reveal the source of the information."

This federal rule accounts for the concern of family members being reluctant to share medical information with providers in fear of their loved one becoming angry and further damaging relationships. It's okay to tell the treatment provider your concern about sharing the information. Hospital or mobile crisis professionals are expected to respect your wishes and act in the best interest of the loved one who's in crisis.

*Updated language in the HIPAA Privacy Rule as published in the *OCR guide* allow for reasonable allowances by hospital mental health professionals to exercise their professional judgment to consult directly with the families of the seriously mentally ill who lack capacity and when in the best interest of the patient. This may include circumstances when a patient is experiencing temporary psychosis. This flexibility allows mental health professionals to consult with family members or guardians, prioritizing the best interests of the patient while upholding privacy standards. Educating mental health professionals on these small, but very significant changes, may be required.

SMI CAREGIVERS IN CRISIS

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HIPAA (CONTINUED)

Be sure to document phone calls with the date, time, and summary of information shared. It is always recommended to follow up with an email or fax after a phone call to ensure there is a record of the communications.

If you do not feel your loved one is safe to be discharged from a hospital setting, put this in writing to the treatment team with the reasons you believe this to be true. Most likely the main point of contact will be the social worker. Social workers are put under tremendous administrative pressure to facilitate discharges AS QUICKLY AS POSSIBLE. But it's important to remember that the ultimate decision about when to discharge lies solely with the attending physician or advanced nurse practitioner. The social worker can advocate with the attending. If discharge is imminent but unsafe, it might be helpful to directly talk with the attending.

Remember, being able to communicate your ideas and expectations for your loved one in a clear and concise manner will not only earn you credibility and respect, but will help eliminate misunderstandings while fostering teamwork and collaboration. Avoid using words that may come across as attacking or placing blame, focusing on what your loved one's needs are and how to best meet those needs. Placing blame and criticizing will only put the staff members on the defensive and increase their anxiety.

Prior to discharge, you are encouraged to inquire about services that may be available to your loved one:

- Assisted Outpatient Treatment,
- Assertive Community Treatment Teams,
- Clubhouses,
- Peer Support Groups,
- Employment Assistance,
- Supportive Housing Options,
- Outpatient Therapy Sessions,
- Medication Management etc.

Family involvement in treatment can lead to better outcomes for your loved ones; when family members actively communicate with healthcare professionals they may receive more attention due to their involvement. Advocating for these services prior to discharge will increase your loved one's chances of success, hopefully eliminating the need for a future hospitalization.

SMI CAREGIVERS IN CRISIS

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AVOIDING CRIMINALIZATION AND POLICE INVOLVEMENT

I am fearful my loved one's behavior will lead to police involvement, what can I do?

Early communication with your local police department is recommended when you have a loved one who struggles with a serious mental illness. Introducing yourself, and briefly describing your loved one's illness can be helpful in the event they come in contact with law enforcement or are called to your house during a crisis. Inquire to see if there is a procedure in place to document this information that you have shared.

Ask about training. Does your police department have a Crisis Intervention Team (CIT)? Is there a CIT clinician on staff? If so, it is recommended to get their contact information so that you can keep them informed if you feel your loved one is deteriorating. Do not be afraid to reach out to the CIT clinician to get their advice before a situation becomes a crisis. Being proactive can often prevent a situation from escalating.

During crisis situations that involve law enforcement, you are under no obligation to provide details leading up to the event. Though many law enforcement are well trained to assist when a mental health crisis does occur, some families have found that giving specific details has led to the filing of criminal charges. It is best to keep it simple; let police know that your loved one is experiencing psychosis and that he or she needs to go to the hospital for medical treatment.

My loved one is in the criminal justice system for committing a crime because of untreated serious mental illness. What should I do?

Sadly, an estimated 2 million people with serious mental illness (SMI) are booked into jails in the United States, highlighting the significant issue of criminalization of those with SMI. Our criminal justice system is often ill-equipped to understand the needs of those with SMI, instead harshly punishing these individuals.

If You Are A Victim

It is critical that judges and prosecutors understand that your loved one is involved in the criminal justice system directly related to untreated SMI. If you are a victim in the alleged crime, you have the right to submit a victim impact statement. This is an opportunity to provide information about your loved one's history of mental illness, the barriers to treatment, and to advocate for treatment in lieu of punishment. Providing this information early on is recommended.

What If I Am Not A Victim?

If your loved one gets arrested while in psychosis, it is important to try and alert the District Attorney's office and the prosecutor of your loved one's history with serious mental illness and to provide education about psychosis and anosognosia. It is recommended to first try to speak with your loved one's attorney. If you are unable to communicate with the defense attorney, a letter should be written, and an attempt made to give it to the District Attorney's office and prosecuting attorney. Identify your relationship with the defendant and let them know that you are providing important medical information. Though the prosecutor may not be legally bound to accept this letter, more often than not they are willing to read it.

The goal is not to get your loved one excused from the crime that was committed, but to ensure they receive the proper medical treatment that was needed to prevent the crime from occurring in the first place. Keep the letter concise while providing details of your loved ones history of SMI.

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SAMPLE LETTER TO JUDGE

Your Honor,

My name is [insert name], [insert name]'s mother. [insert name] is [insert age] years old and was diagnosed with schizophrenia at the age of [insert age]. When experiencing psychosis, xxxx experiences hallucinations (he hears and sees things) and delusions (false-fixed beliefs), which he believes 100% to be true, despite making no sense to those around him. He also suffers from anosognosia, the inability to recognize his illness thus unable to recognize he needs medical treatment. Anosognosia is a symptom that more than 60% of those diagnosed with schizophrenia experience. Unfortunately, the state of [insert state] does not offer any options to get my son the medical care he so desperately needs until he becomes a danger to himself or to others despite his increasingly erratic behavior.

I have become an expert in recognizing when my son is in a crisis and needs help. With countless involuntary hospitalizations over the years, when [insert name] was experiencing his most recent psychotic episode, I knew that he was in a crisis and needed medical treatment. Despite calling the crisis mobile team and 911 the day before the alleged incident, I received no help, and my son was left in the community as he continued to deteriorate.

As a result of untreated psychosis, my son was making threats and being disruptive. Unfortunately, the laws in [insert state] remain a barrier to getting those with severe mental illness the medically necessary treatment that is needed before a crisis occurs.

As [insert name]'s mother, someone who has had to be the voice for my son who lives with severe mental illness and is voiceless, I ask your Honor to consider sending him to a hospital where he will get the right help. Jail cannot help a person with a serious mental illness, it will only contribute to his symptoms worsening. It is my hope that our state will stop criminalizing those with mental illness, serious mental illness deserves treatment not time.

Respectfully,

[insert name]

BE ENCOURAGED

Many courts have mental health courts that serve adults involved with the criminal legal system. Mental Health Courts are designed to increase access to mental health treatment for court-involved individuals and assist them in their path away from unlawful behavior. A defense attorney, prosecutor, probation officer, or judge can request a mental health court screening. If your loved one is involved in the criminal justice system, you should ask if there is a mental health court available.

No matter what you are going through, remember that you are not alone. National Shattering Silence Coalition offers support groups for Caregivers where you can connect with others in a supportive environment. Please visit our website at nsscoalition.org for more information.

MORE FROM NSSC

SPEAKING OUT - INSPIRING CHANGE FOR SEVERE MENTAL ILLNESS/BRAIN DISORDERS

NSSC offers more guides on our website (nsscoalition.org) – including:

Guide to Advocating for Policy Reform (Recommendations for Meeting with Your Federal, State and Local Government Officials, and Leveraging Your Messages)

Member-Exclusive Resource Guide (join us today for your free issue)

Guide to Psychosis and Psychotic Illnesses (A Peer's Perspective)

These and more resources on our website and social media.

THE SANDY PRUETT PROJECT

RAGE: AGAINST DENIED CARE

At the NSSC, we hear from families who live in the shadows—people who've had to step back from someone they love because of untreated Severe Mental Illness (SMI). Are you one of those families?

Now, there's a place for those voices to be heard.

What Is the Sandy Pruett Project?

The Sandy Pruett Project is a safe, anonymous storytelling platform for families who live (mostly) in silence.

Every story submitted is reviewed, lightly edited for clarity and safety, and then shared publicly under the name Sandy Pruett.

There are no names. No blame. Just truth.

These stories are not for sympathy. They are for systemic change.

We are compiling them to show legislators and policymakers what happens when families beg for help—and none comes.

When people with SMI fall through every crack. When silence becomes the only safe option.

Why "Sandy Pruett"?

Sandy Pruett is not a real person. She is a collective voice. And she is speaking now.

Who Is This For?

The mother who sleeps with her bedroom door locked.

The parent whose loved one committed violence and can't risk stigma.

The family navigating media attention after a tragedy.

The father who dreams of reconciliation—but isn't able to speak publicly.

This project is for anyone whose real name cannot be attached to their real story.

Whether your silence is for safety, privacy, or survival—you belong here.

How to Share Your Story (Anonymously)

If you're one of these families, you're not alone. We see you. We believe you. And we've made a place for your voice to be heard—without being exposed.

Submit your anonymous story through the QR code below:

Your story will be shared as part of the Sandy Pruett Project on social media and in advocacy materials—so that even those who can't speak publicly are finally included in this fight.

No names. No blame. Just truth.

SCAN ME AND JOIN THE MOVEMENT

NATIONAL SHATTERING SILENCE COALITION
for Severe Mental Illness

FIND MORE NSSC ON:

- We're here on Facebook (**facebook.com/NationalNSSC**), feel free to join in the posts in comments and see what our members are sharing in their region.
- We're here on YouTube (**youtube.com/@nsscofficial/videos**) so feel free to subscribe and watch recordings of past Peer and Pro Talks, Subject Matter Expert interviews with host Eric Dias, and the latest press conferences and news.
- We're here on LinkedIn (**linkedin.com/company/nationalshatteringsilencecoalition**) making waves on the platform and growing. Mention #NSSC, #ShatteringSilence, or #FamiliesLikeOurs and make some social media noise!
- We're here on X (formerly Twitter), (**twitter.com/nsscoalition**) adding to the conversation on Serious and Severe Mental Illness. Come join us!
- We're here on our website: **NationalShatteringSilenceCoalition.org** or **NSSCoalition.org.** Check out our updates and news from Who We Are (including our Index of State Policy Directors, Partners, and Team) to Media (blog posts) to Events, to exclusive and free Resources!
- Email us anytime! Shout out to **coordinator@nationalshatteringsilencecoalition.org**!