

# 15 Ways To Support a Loved One with Serious Mental Illness

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Supporting a loved one with mental illness presents many challenges. But one of them isn't blame. It's important for families "to learn that they didn't cause [their loved one's disorder] and they can't cure it," according to Harriet Lefley, Ph.D, professor at the Department of Psychiatry & Behavioral Sciences at the University of Miami Miller School of Medicine who's worked with families for 25 years.

Still, how you treat your loved one has a big impact on their well-being. "But their behaviors can exacerbate the symptoms," she said. In fact, Dr. Lefley cited a large amount of literature on expressed emotion that found that patients of families who expressed hostility and criticism toward their loved one (e.g., believing the patient was lazy) or were emotionally overinvolved (e.g., "I'd give my left arm if he'd get well") were more likely to relapse.

Below, Lefley and Barry Jacobs, PsyD, director of behavioral sciences at the Crozer-Keystone Family Medicine Residency Program, Springfield, PA and author of *The Emotional Survival Guide for Caregivers*, offer their tips for effective support.

## 1. Educate yourself about the illness.

Educating yourself about your loved one's illness is really the foundation of support. Research also has shown that education works. According to Lefley, a huge body of evidence has shown that if you provide families with education and involve them in the treatment process, patients experience a reduction in symptoms, hospitalization days and relapse. Plus, the family environment is generally improved, she said.

Not knowing how the illness functions can create misconceptions and prevent families from giving their loved ones effective help. For instance, without education, it's hard for people to grasp and appreciate the severity of the symptoms, such as the terrifying thoughts associated with schizophrenia or the suicidal ideation associated with a deep depression, Lefley said. It's not uncommon for families to wonder why their loved ones just can't snap out of it.

Families must "understand that the [individual's] thoughts and actions are not under their control," Dr. Jacobs said. Any antagonistic or bizarre behaviors are a manifestation of the illness, not willful, purposeful actions.

Similarly, in families, there is "a tendency to personalize a loved one's symptoms and behaviors," Jacobs said. However, these behaviors "are not meant to cause friction in the family," Lefley said.

## 2. Seek out resources.

One helpful way to educate yourself about a loved one's illness and how you can help is by turning to reputable publications. Lefley recommended the following books as excellent resources.

- *The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life* by Kim T. Mueser and Susan Gingerich
- *Surviving Schizophrenia: A Manual for Families, Patients and Providers* by E. Fuller Torrey
- *Schizophrenia for Dummies* by Jerome Levine and Irene S. Levine
- *The Bipolar Survival Guide: What You and Your Family Need to Know* by David J. Miklowitz

You also can learn more about all psychological disorders here.

### **3. Have realistic expectations.**

Your expectations can impact your loved one's recovery, too. According to Lefley, the following (with different variations) is an all-too-common case:

A loved one spends several weeks in the hospital. When they're out, the family assumes that the hospital stay has cured them. The individual wants to make up for lost time at school, so they ramp up their class schedule by taking extra courses. By doing so, their stress level escalates and they end up having a relapse. In this case, the best option is to have lower expectations and encourage a loved one to set a slower pace since added stressors can exacerbate symptoms. Families may not realize that "every time the person has a psychotic episode, more and more neurological damage" occurs, Lefley said.

But setting reasonable expectations can be tricky, as Jacobs pointed out, because "we aren't talking about a static illness." Families are trying to "adjust their expectations to a moving target," so the challenge is to "fine-tune those expectations all the time given the trajectory of the illness," which he said may change "week to week, day to day or even hour to hour."

Sometimes, you may be using pure trial and error, Jacobs said. But using your own experience can be helpful. "Ultimately you'll know a whole lot more than any professional will," he said, so it's important to have realistic expectations and to encourage your loved one to have them, too.

### **4. Reach out for support.**

Stigma can prevent families from seeking support. But it's through support that you can gain more strength and valuable knowledge. Support groups also help to "normalize [a family's] experiences and better enable them to swap ideas about managing a loved one with mental illness," Jacobs said.

The National Alliance on Mental Illness (NAMI) is a great resource in helping to support families and educate them on mental illness. For instance, NAMI offers a free 12-week course called the Family-to-Family Education Program, and most areas have local support groups. Mental Health America (MHA) also offers a variety of programs and resources.

### **5. Work closely with your loved one's treatment team.**

While it depends on the specific system, confidentiality barriers and HIPAA laws can complicate working with your loved one's treatment team. But this is a challenge you can overcome. In fact, Lefley tells families that "it's worth it to make a pest of yourself."

First ask to speak to your loved one's social worker and the psychiatrist, if possible, she said. Let them know that you'd like to be part of the treatment team. "Many facilities will allow families into the meetings and case conferences," she said. But ultimately, families should ask to be included and "expect it."

Ask how you can help your loved one, and "find out what's a reasonable expectation for recovery and how functional will [your loved one] be," Jacobs said.

### **6. Let your loved one have control.**

"People with mental illness feel they've lost control of their lives, they feel stigmatized and they suffer the most with self-esteem," according to Lefley, who said that this is the most important point she tells families. "Treat them with respect no matter how symptomatic they are."

Say your loved one is smoking too much, for example. Don't chide them about this or try to hide their cigarettes. The same goes for "decisions that aren't that important," she said. If their outfit doesn't match, leave it alone. "Leave those decisions about the small things in life up to the patient," she said.

Even seemingly bigger decisions, such as schedules for taking medication, may be better left to the patient. For instance, Lefley said that patients hate being asked whether they've taken their medication. The best way to handle this is to set up a system with your loved one, which is easier to do after they returned from the hospital. One system is to have a weekly pill box and help them chart their medication.

Similarly, "If a person wants to do something that you feel is beyond their capabilities, don't immediately deny them the opportunity to try," Lefley said. Oftentimes you'll find that they are able to do it.

## **7. Encourage them to talk to their mental health professional.**

If your loved one is complaining about adverse side effects from a medication, encourage them to write down what bothers them and talk to their doctor, Lefley said. Even in her support groups, patients who are "pretty well stabilized and taking care of their own treatment, hate to disturb their doctor with [any concerns]."

Remind your loved one that they're "in control of their bodies" and are active participants in their treatment.

## **8. Set appropriate limits.**

While it's important to treat your loved one with respect and allow them to exercise control, it's just as necessary to set limits for the sake of everyone's well-being. Jacobs told the story of a 25-year-old man with severe type 1 bipolar disorder. He was living with his parents and younger siblings. Several years before, he decided to stop taking his medication because of the side effects. "The family basically tolerated his aggressive behavior for a really long time, even though it had negative consequences for the younger children and it began to escalate." He was getting into altercations with the neighbors and even the police were called on several occasions.

Even though his parents were trying to provide him with dignity, Jacobs said, instead they allowed him to make choices that were harmful to himself and everyone. After working with Jacobs, the parents talked with their son and informed him that in order to live in their house, he'd have to seek treatment and take his medication. Consequently, "He was far less aggressive and was in a position where he could go forward in his life and become a full-fledged adult."

Jacobs explained that this is a fairly typical scenario. Families "don't want to step in too much and give mandatory conditions but at the same time, there are family members who basically say 'you'll do it my way or the highway,' in a very punitive and harsh way." As mentioned earlier, this approach "doesn't give the individual any option to live their life."

## **9. Establish equality.**

When setting limits and supporting your loved one, don't single them out as the sick one, Lefley said. Instead, "establish some kind of equality of what is expected of everyone in the household." Lefley teaches families problem-solving strategies so everyone, the patient included, can voice their concerns and contribute to creating solutions.

For instance, when it comes to aggressive behavior, the family can agree that this won't be tolerated in the household from anyone. "The more you can equalize [the situation], the more therapeutic it is," she said.

## **10. Realize that feelings of shame and guilt are normal.**

Know that guilt and shame are typical reactions for families, Lefley said. Some families may worry that they didn't get their loved one into treatment sooner; others may think they caused the disorder. Again, recall that families don't cause mental disorders like schizophrenia or bipolar disorder—they're caused by a variety of complex factors, including genetics and biology.

## **11. Recognize your loved one's courage.**

In our society, we view people with a physical illness, such as cancer or diabetes, as courageous, but we don't extend the same perspective to people with mental illness, Lefley said. But it takes enormous courage to return to normal life after being hospitalized, she said. It takes courage to battle the debilitating symptoms every day and to seek and stay in recovery.

## **12. Help yourself.**

One of the biggest issues Jacobs faces with caregivers is their refusal to accept help. But "you're in a much better position to help out and give again" if you help yourself, he said. It's also unhelpful to concentrate all your efforts on the individual with the disorder, Lefley said. This can alienate siblings and other family members, as well.

## **13. Be calm.**

Because your actions can influence your loved one and impact their symptoms, "avoid responding angrily," Jacobs said. Instead, respond with patience and understanding, he said.

## **14. Convey hope.**

Inform your loved one that with continued treatment, recovery—"lead[ing] a satisfactory life in the community despite the illness"—is possible, Lefley said.

## **15. Get political.**

Lefley encourages families to get involved in the political process of improving the mental health system since this affects families and their loved ones. You can browse NAMI and MHA to see what you can do.