

# The Family Role in Recovery: Understanding the Illness and Embracing the Process

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The fear and distress are unimaginable when serious mental illness strikes families. They become confused when their loved one acts in an erratic or unfamiliar way and may feel helpless when a child or adult refuses treatment. New concerning behaviors emerge, and aspects of their loved one's personality may seem lost.

Families often feel anxious and bear feelings of guilt that they are the cause of the problem. Denial of the illness is a natural response at first. Grief and recognition follow with the reality that this is an illness that is here to stay. Families are an extremely important component of the recovery process, and their roles are complex. Families need to learn how to meaningfully participate in recovery and realize that their acceptance will positively impact how a loved one responds.



## Understanding Individually-Defined Recovery

“The common clinical definition of recovery often implies something akin to a cure,” states Lisa Dixon, Director of the Center for Practice Innovations at the New York State Psychiatric Institute. The prevailing, if unspoken, view is that this type of recovery is rarely possible for people with serious mental illness. The individual-focused recovery involves a state of hope, empowerment, and personhood, resembling more of a process than an end-state or an outcome. Dixon explains that “the research world has just started to connect with the challenges posed by the consumer perspective on recovery.” According to Dixon, shared decision-making models, clinical partnerships, and peer-based programs may provide a solid framework to promote recovery in clinical care.

## Managing Expectations and Stress

Eric Leventhal, a senior social worker at the outpatient clinic at Bellevue Hospital, a private practice psychotherapist, and board member of the National Alliance on Mental Illness of New York City (NAMI NYC Metro), explains that “families need to be educated about the illness and learn how to communicate effectively with their loved one in order to foster better results.” According to Leventhal, just being involved is not enough, unless it's the right kind of involvement. Effective involvement is not always easy to achieve, especially when families place high expectations on their loved ones.

“There needs to be an understanding among families that individuals who are mentally ill may not want the same things that healthier people want and may be happy living a simple life,” he states. Certain behaviors are often difficult for families to understand, however, families must try to accept that individuals struggling with mental illness may not be connected to their environment the way healthier people are and may live life differently. It also does not mean that the family or the family member with mental illness is a failure,” explains Leventhal.

Besides managing expectations, families must learn how to minimize stress. “It can often be stressful for a family living with an individual who is mentally ill, which brings a lot of emotions to play in the household. If you keep the emotional temperature in the house low and remain calm, the individual who is ill will usually respond much better,” says Leventhal.

Michael Andersson, a NAMI NYC Metro [Peer-to-Peer](#) course facilitator and an adult with a dual diagnosis of bipolar disorder and PTSD, recalls his days of living with his family: “It just brings out all the bad habits and with the illness on top of that, it is just a nightmare.” Fortunately for Andersson, his family eventually enrolled in

**NAMI's Family-to-Family** course. "It was a huge transition for them once they completed the course. They finally had an understanding of my illness and stopped blaming me. It was a huge relief," Andersson explains.

## Acceptance through Education and Support

It's true that those families who recognize the importance of educating themselves will eventually learn that mental illnesses are biologically-based brain disorders, and just like any physical illness, there are signs to look for. Until the biological basis is understood, however, feelings of anger, guilt, and denial will prevail and acceptance of the illness will remain difficult.

Acceptance certainly took some time for Deniece Chi-David, **NAMI Basics** coordinator, whose daughter was diagnosed with bipolar disorder as a child. "Within the Latina culture, the stigma within my family was so strong. It took me a long time before getting my daughter proper services and treatment because my family didn't believe in it and blamed my daughter's condition on me not disciplining her enough," she recalls.

According to Chi-David, families need to understand that support systems are important, but it doesn't mean that they have to be limited to immediate families. "There's this mentality that families need to rally around each other when a loved one is physically ill. But, if the stigma surrounding mental illness exists within families, it is OK to reach out to friends, church groups, even total strangers as support systems," says Chi-David.

"I don't know how families get through without the support and the knowledge base," states Jennie Megibow, a social worker and NAMI Family-to-Family graduate whose adult son has schizophrenia. For Megibow, the most valuable information she gained was learning to communicate in a way that her son understood her. "You have to be non-threatening, encouraging, and have a sense of humor. If I didn't have a good sense of humor, I would be lost," she states.

## The Crucial Role of the Family in the Hospital Setting

Support systems can be particularly helpful when families experience the hospitalization of a loved one. During this time, families need to recognize that they contain valuable information about their loved ones and are able to separate them from their illness. "The hospital stay is a critical time for families to get involved and to provide information to the treatment teams, such as history of behaviors or what types of responses they may have to certain medications," explains Leventhal. Hospitals are busy, high-stress places, and families need to remain assertive. It's difficult to continually follow-up and ask questions or take the time out of a workday to come and meet with treatment teams, but it's a vital part of the recovery process and learning how to effectively advocate for a loved one will go a long way.

"Families can serve as valuable contributors after an initial history is taken," states Patti Sacher, a NAMI Family-to-Family course facilitator and the mother of an adult consumer who has been hospitalized eight times since 1989. "Families must be attentive and aware of the fact that during the hospitalization of a loved one, an exact diagnosis is often difficult, and effective medications can take time to find, often change, and can have strong side effects," she explains. Families need to know that some people with serious mental illness are unable to accept their illness, which is actually a symptom of the illness itself. "No one with lack of insight suddenly gains insight during a three, six or even eight week hospitalization," explains Sacher. Many times, this 'lack of insight' will lead to non-adherence to treatment, which many families find extremely challenging. "Once families do gain better understanding, hospitalizations can provide vital stabilization and an opportunity to begin the process of recovery, but it takes time," she says.



## Time Matters

The element of time plays an important role during the recovery process for families. It is not uncommon when loved ones are first diagnosed that family members believe that once they are given the medication they will be OK and be able to continue on with their daily lives. Often families need to rethink expectations of a quick recovery and understand that there may be permanent changes in some treasured aspects of personality and motivation, but that does not mean that recovery is not possible. Families need to be patient. With effective outpatient treatment, therapy, time, and, of course, knowledge, families will see their loved ones begin to heal.

### **Sibling Involvement**

Families can learn to integrate their loved ones' mental illness into their lives without having it take over, and siblings can play an important role. "The sibling relationship is unique because it's the longest relationship a patient will have. It's comforting for people with mental illness to know that someone else is going to be involved in their care when their parents are no longer around," states Leventhal. While some siblings choose not to be involved at all, many families have found ways to assign roles to each member of the family so that one person does not take the entire burden.

While siblings play an important role, the parents of multiple children must recognize that different treatment is needed for those with mental illness and those without.

"As a parent, you work within your family to accommodate the needs of your child, which is very difficult if you have other children. It took me five years of living with my daughter to realize that I couldn't parent her the same way that I did with my older daughter," explains Karen Jacoby, NAMI Basics facilitator and mother of a child with bipolar I.

### **The Bottom Line**

There is strong evidence that shows family participation in the care of individuals with mental illness contributes to improved outcomes for both the individual and their family. Unfortunately, family participation does not occur in the majority of cases of adults with mental illness. When mental illness strikes a family, the absence of knowledge drives unreasonable expectations regarding recovery and acclimation. This undermines the sufferers' very fragile sense of self and hinders the treatment process. Effective engagement will only come once families educate themselves and learn ways to meaningfully integrate the illness into their everyday lives.

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