On my mind: What to do if you have a mentally ill family member?

Here are two facts: First, when there is family involvement in the care of people with serious mental illnesses, everyone does better. Second, family involvement in mental health care does not occur in the majority of cases. According to Lisa Dixon, M.D., who is the director of the Center for Practice Innovations at the New York State Psychiatric Institute and a professor at Columbia University Medical Center, the single most important intervention for families of adults with mental illnesses is the 12-session Family to Family course offered by the National Alliance on Mental Illness (NAMI).

Family-to-Family is free and has proven efficacy. As its name suggests, it is led by and open to family and friends of people living with a mental illness.

Recently I attended two F2F sessions and spoke with several teachers of the course here on Martha's Vineyard. I was profoundly impressed by the kindness,

wisdom, and knowledge of the people I heard and met there. Family members of people suffering from the broadest array of mental illnesses were there. I truly regret that despite over 35 years in the mental health field, I had never been to a NAMI meeting until recently.

I know how challenging it is for people with serious mental illnesses to access care, how frustrating it is to take medications with sometimes debilitating side effects, and how sad and infuriating it can be to watch a family member suffer from severe depression, psychosis, or substance abuse. When I agreed to attend the NAMI meetings, I expected to encounter family members who were feeling angry, frustrated, and helpless. When I commented on that, I was told that if I had come to class 1 or 2 rather than 10 and 11, that is exactly what I would have found. But the group that I met was welcoming, appreciative, and filled with hope.

The first class I attended began with members taking turns talking about how they had implemented the previous lessons. One woman described how, when her son was yelling at her, rather than yelling back, she kept the focus on herself: "Jimmy," she told him, "when you raise your voice, I get scared and nervous." To her astonishment, he replied, "I'm sorry, Mom." And he lowered his voice.

One parent reported that her daughter wouldn't clean her room, left the house a mess, and when confronted, stormed out of the house after kicking the dog. A list was made of the parents' concerns, including: The other parent was enabling; if the child needed hospitalization she would refuse to go; the home was chaotic, and the parent was overwhelmed; the child didn't like her therapist. After listing the problems presented, the teacher asked the question, "What is the most pressing of these problems, and what can we do to fix it?" The group decided that the most pressing problem was that the daughter wouldn't take her medication because it was making her gain weight.

"So let's troubleshoot that single problem," said the teacher. The class listed possible solutions. "Talk with her psychiatrist," one person suggested. "The psychiatrist won't return my calls," replied the parent. That roadblock triggered another set of solutions. "Call and leave a message. Even if he won't talk with you, he will listen to a message." "Just show up at the next appointment and walk into the room with your daughter," someone else suggested. "Speak with the primary care doctor," was another suggestion.

Class 11 focuses on how to be an effective advocate. During that session, we talked about how anyone entering the mental health system (or anywhere in the

health care system) needs an advocate. The teacher focused the group on how to make the care team a finely oiled machine that works together to support the person who is suffering from an illness. She discussed how far too often, without training, family members who can understandably be frightened and angry can be seen as obstacles by the health care team. The class trained in how to work with the health care team so that everyone is working together toward a common goal.

It is hard to know whether to call these sessions meetings or classes; in fact they are both. Here is the order of the classes: 1) Normal reactions to having an ill family member. 2) Understanding mood disorders and schizophrenia. 3) An overview of psychiatric illness — with and without substance abuse. 4) Basics about the brain. 5) Problem-solving workshop. 6) A review of psychiatric medications. 7) Understanding the challenges of having a mental illness. 8) Communication skills workshop. 9) Self-care. 10) The vision and potential of recovery. 11) Advocacy, and 12) Review and sharing. It is a wonderful class in its own right. But as one teacher told me, “Half the value comes from the training. But the other half comes from the comfort of feeling less alone, having a sense of community, and the bonding that occurs for the group. The group often forms lasting friendships that are sustaining and helpful to everyone.”

Having a family member with depression, substance abuse, or psychosis can be devastating for family members. Spouses often feel betrayed, abandoned, and desperate. Parents can feel crushed by failed dreams and the weight of caring for an adult child, and siblings often long for the attention that is focused on their brother or sister.

One class graduate said this: “The initial years in a nutshell: lack of understanding and insight, and so much to overcome alone. A game of push and pull of mental illness, substance use, and a loved one caught. The bouncing back and forth from mental health systems, substance use treatment programs, multiple three-week hospitalizations, and steadily worsening symptoms was not working. I was angry all the time. I couldn’t hide it. I was so disdainful of what I saw as his weakness. So we avoided each other. He became more isolated. I suppose so did I. My friends were sick of hearing about it. I had the attitude that my brother should just pull himself up by his own bootstraps, as I had done. But by the second class, I came to realize that sometimes he has no bootstraps. I became more loving and compassionate. Listening to others’ stories at F2F and bonding with so many strong and wonderful people created a shift in me. It was alchemy. My anger at my brother turned into love. My helplessness and anger has been turned into

advocacy. I continue to work at it. I am committed to an emotional sobriety. I enjoy a new life full of promise and see this journey as a gift. I am a better person and am grateful for it. All is well now: My brother has full-time work and the right medication and support, and we have a renewed connection."

This class clearly helps all of the family members who take it and stay. (I am told that 75 to 90 percent of the people who walk into the room remain through class 12.) One question that I had, however, was, "To what extent does it really help the patient who is suffering with the illness?" To some extent Class 10 answered that question. An hour or more is devoted to a presentation entitled "In our own voice," by two people who tell their stories about their recovery from mental illness. The stories were moving, inspiring, and full of hope. They proved that recovery can happen, that teamwork paves the way for it, and that multiple sources of help are available.

One of the speakers had suffered from a depression so severe that she became severely paranoid and lost touch with reality. In the course of her illness, she lost her marriage and for some time, her children. Her parents, who were initially confused, angry, and beside themselves with worry, took the Family to Family course. They learned to be kind, supportive, and superb advocates for their daughter. She recovered, got her children back, and is now happily working full-time, and is as clearheaded as the best of us.

Dr. Lisa Dixon led a randomized study of 318 individuals, half of whom took the three-month Family to Family class right away, while the other half waited three months to take it. She and her colleagues found that the participants came away with a sense of empowerment, and greater knowledge and ability to access help for family members. Participants experienced improvements in mood, problem-solving, and acceptance of mental illness. As a result of Family to Family, there was less distress, depression, and anxiety. And the growth lasted long after the course was over.

One of the things I appreciate about living in a small community is that it forces a kind of honesty. It is hard to escape that we are more aware of each other's behaviors, practices, and attitudes than in a big, anonymous city. In medical school, I was taught that I should be the expert in the room. I was told that being the expert would comfort my patients. So I have worked hard to be an expert. We physicians often come to think that we are at the center of the healthcare system. But as Dr. Dixon told me, "We are just in a little corner of the universe that comprises the life and care of someone suffering from a mental illness." There are

many reminders that doctors are not and should not be the only expert in the room. In some ways, the most important experts are the people suffering from illness and those people's family members and support systems. In attending the Family to Family class, I was reminded that when we work together as a team, everyone benefits, and the patient gets the highest level of care.

The class is offered once a year on Martha's Vineyard. NAMI on MV also has a support group that meets on the first Sunday of the month from 6 to 7:30 pm at Island Wide Youth Collaborative. They can be reached at namimvy@yahoo.com with questions, or visit the website at namicapecod.org.

Dr. Charles Silberstein is board-certified in general, addiction, and geriatric psychiatry, and is the psychiatrist at Martha's Vineyard Hospital. He writes regularly about issues Islanders have with mental health.