

# Impact of Mental Illness on Families

## Understanding Denial

When mental illness first strikes, family members may deny the person has a continuing illness. During the acute episode family members will be alarmed by what is happening to their loved one. When the episode is over and the family member returns home, everyone will feel a tremendous sense of relief. All involved want to put this painful time in the past and focus on the future. Many times, particularly when the illness is a new phenomenon in the family, everyone may believe that since the person is now doing very well that symptomatic behavior will never return. They may also look for other answers, hoping that the symptoms were caused by some other physical problem or external stressors that can be removed. For example, some families move thinking that a "fresh start" in a new environment will alleviate the problem.

Sometimes, even after some family members do understand the reality of the illness, others do not. Those who do accept the truth find that they must protect the ill person from those who do not and who blame and denigrate the ill person for unacceptable behavior and lack of achievement. Obviously, this leads to tension within the family, and isolation and loss of meaningful relationships with those who are not supportive of the ill person.

Families may also have little knowledge about mental illness. They may believe that it is a condition that is totally disabling. This is not so. However, it is difficult to know where to turn to get information. Without information to help families learn to cope with mental illness, families can become very pessimistic about the future. The illness seems to control their destiny rather than the family, including the ill member, gaining control by learning how to manage the illness and to plan for the future. It is imperative that the family find sources of information that help them to understand how the illness affects the person. They need to know that with medication, psychotherapy or a combination of both, the majority of people do return to a normal life style. It is also imperative that the family finds sources of support for themselves and resources in the community that can help the family build the knowledge base that will give them the tools to assist their loved one and themselves.

## Understanding Stigma

Even when all members of the family have the knowledge to deal with mental illness, the family is often reluctant to discuss their family member with others because they do not know how people will react. After all, myths and misconception surround mental illness. For many, even their closest friends may not understand. For example, the sister of a young man with schizophrenia pointed out that when a friend's brother had cancer, all his friends were supportive and understanding. But, when she told a few, close friends that her brother has paranoid schizophrenia, they said little and implied that something must be very wrong in her family to cause this illness. Family members may become reluctant to invite anyone to the home because the ill person can be unpredictable or is unable to handle the disruption and heightened stimulation of a number of people in the house. Furthermore, family members may be anxious about leaving the ill person at home alone. They are concerned about what can happen. The result is they go out separately or not at all.

The result of the stigma in so many areas of daily life, is that the family becomes more and more withdrawn. When others do not accept the reality of mental illness, families have little choice but to withdraw from previous relationships both to protect themselves and their loved one. They are unwilling to take any more risks of being hurt and rejected

## Understanding Frustration, Helplessness and Anxiety

It is difficult for anyone to deal with strange thinking and bizarre and unpredictable behavior. Imagine what it must be for families of people with mental illness. It is bewildering, frightening and exhausting. Even when the person is stabilized on medication, the apathy and lack of motivation can be frustrating. A mother mentions how her daughter, when asked to put her clothes in the closet, looked at the freshly pressed blouses for over an hour before making a move to hang them up. What was a matter of routine for this young woman in the past, now seemed to take an inordinate amount of time. Even though the parent knew it was not so, she had to fight the feeling that her daughter was deliberately not doing this one, small task.

Another parent described how her son would no longer come out of his trailer home to get food to make a meal. So, she became a delivery service. She brought food to the trailer, left it outside and hoped her son would open the door and take the food. He only did so after she left, because he did not want to speak with her, as he believed that if he spoke to her, aliens would "zap" her and she would become one of "them" This went on for eighteen months, until his situation deteriorated to a point where he was deemed a "danger to himself and others," and was hospitalized. The ongoing pressure and dismay for this mother was a burden that took a terrible toll on her as she coped the best she could with a very disturbed son and a mental health system that did not view her son as so ill that he could access treatment. This parent went from agency to agency and from advocacy group to advocacy group seeking help for her son. In time, that help came. But, during those eighteen months of anguish, she lost weight, slept fitfully and had crying bouts at work.

Family members may have trouble understanding any difficulties the person is having, or they may tell themselves that the person will "snap out of it" if given time, support and encouragement. Families may become angry and frustrated as they struggle to get back to a routine that previously they have taken for granted. How much easier to believe everything will go on as before, rather than to focus on the changes and adjustments the person and the family must make. This behavior often results in the family going from crisis to crisis, without any plan to deal with the situation. They become more and more frustrated and bewildered because both the ill person and the family have no control and no understanding of what is happening.

Obviously such constant stress and concern can create serious family problems. Family life can be unsettled and unpredictable. It becomes very difficult, often impossible, to plan for family outings or vacations or to have even the simplest gathering at home. The needs of the ill member become paramount. At the same time there remains the needs of other family members and the usual problems of everyday life. For siblings this can be very painful. It appears that their needs, their time to have the focus on them, are put off or ignored. In some cases the parents disagree on what should be done or find that caring for the ill person leaves them too exhausted to give much attention to their partner. This very draining experience can create an atmosphere of confusion and resentment, which can result in irreparable damage to the family.

### **Understanding Exhaustion and Burnout**

Often families become worn out and discouraged dealing with a loved one who has a mental illness. Having gone down many dead-end streets in an attempt to find assistance, they may be hesitant to try another approach for fear of another failure. They may begin to feel unable to cope with living with an ill person who must be constantly cared for. Hopefully they can develop a plan to allow each family member to take responsibility for different tasks and/or to trade off times of primary responsibility. But often, they feel trapped and exhausted by the stress of the daily struggle, especially if there is only one family member. Friends and relatives

can alleviate the situation by offering to assist the family with some of the care responsibilities. This may mean taking the person out for a drive, getting the person to an appointment, bringing in a meal, offering to spend time with the person to relieve the family, etc.

Families may feel completely out of control. They may be at their wit's end, believing that it is impossible to predict what will happen from day to day. This may happen because the ill person has had no limits set on his/her behavior. The person may rule the family as a tyrant who is demanding, threatening, and refusing all efforts to help him/her alter unacceptable behavior. This is especially likely to happen when the ill person is unable, because of the illness, to understand the effect of his/her destructive behavior. Families may say they can no longer stand the abusive behavior, the threats, the living in constant fear, and the constant talk of suicide. It is imperative that the family is referred to a mental health professional, such as a social worker, and a support group, such as the Alliance for the Mentally Ill or the Depressive and Manic Depression Association. These resources can assist the family in making a plan to manage a volatile situation and in setting limits. Families need to be reminded that in the light of all the pain they see around them, they are bound to feel helpless at times. They should be able to admit this without shame. They should know that in caring and in being there, they are doing something that is vital for their ill loved one.

### Understanding Grief

One of the greatest difficulties for families in accepting any life altering illness of a loved one is dealing with a changed future and expectations. The grief is particularly acute for families where a loved one has a mental illness. This illness impairs the person's ability to function and participate in the normal activities of daily life, and that impairment can be ongoing. Families struggle with accepting the realities of an illness that is treatable, but not curable.

Imagine how it must feel watching others finish their education, get jobs, and have families while your child is struggling to obtain a G.E.D., barely holding on in a supported living arrangement, and having lost his friends, one by one, as their lives have less and less in common. Families grieve for what might have been and find it difficult to focus on the possibilities that remain for their loved one. Very often they see the person as having substantially diminished potential rather than as having a changed potential. Without a caring place, without someone to be with them through this grief process, they may never come to accept the illness. Of course the pain may never go away. But, working through their grief allows them to accept what has happened and to move on. In these situations a pastor can be a supportive listener who understands the need for this process and the presence of someone to help.

Families may ask why mental illness has struck this family. They need to know that, just as with any serious illness, there may be no good answer. It is no one's fault, it is simply an illness that has struck just as cancer, diabetes, or heart disease can strike. In this situation, the pastor can assist the family to turn their questioning toward learning about the illness and how to handle it. The added assistance of a support group, such as the Alliance for the Mentally Ill or the Depressive and Manic Depressive Association can be most helpful to the family. They will find others in these groups who have experienced some of the same problems and concerns. They will be able to find that they are not alone, that others have found answers and that with sufficient resources things can improve for them just as they have for others.

Family members may find that mental illness is so devastating that it is hard to bear. However, just as with multiple sclerosis, diabetes or a disabling accident that strikes young adults, the family must guard against pity or placing the ill person in the role of victim. The entire family, including the person who is ill, should be encouraged to look to the future with a plan for dealing with the illness. Certainly this can be difficult and time consuming, but it will lead to

building on and strengthening the person's and the family's assets rather than concentrating on deficits. Again, a mental health professional and a support group can be very helpful in assisting with this process.

**Understanding the Need for Personal Time  
and to Develop Personal Resources**

**Avoid placing blame and guilt:** Recognize that you are a loving family member and/or friend and not a magician. None of us can change anyone else, we can only be supportive of ourselves and our loved one as each of us attempts to find ways to manage mental illness. Focus on the good things that happened during each day. Realize that we all have physical and emotional limits. Do not blame yourself or others if that limit is reached.

**Look for support:** Learn to give support, praise and encouragement and learn to accept it in return. Use a support network regularly for empathy, reassurance, affirmation and refocusing. Attend a support group (see listings in the "Community Resources" section). Accept practical, appropriate assistance from educated family members and friends.

**Seek relief from stress:** Find a pleasurable place to go each day. Find a place where you can be alone. Use it whenever you need it. Be gentle with yourself. Spend some time away from the person with mental illness. Avoid activities that increase your levels of tension. Inject some humor in your life.

**Learn to gain control of your life:** Learn to set limits and to make choices. Learn to say "no" and mean it. If you can't say "no," what is your "yes" worth? Use the expression "I choose to" rather than "I have to," or "I should." Learn to say "I won't" rather than "can't." Take care of your own nutritional and sleep needs. Establish short term and long term goals for yourself. You may find it helpful to keep a journal.

**Continue outside interests:** Realize that you should continue your leisure activities, your church activities, your relationships with others, your hobbies, etc. Remember to find times every day, however brief, to enjoy life. Get plenty of physical exercise.

**Learn about the illness:** Learn about resources. Learn what to do if a crisis occurs.