

Impact of Mental Illness on Families

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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. In both cases, clergy can play a critical role in identifying 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. Not surprisingly, all of this can lead to withdrawal from actively participating in the life of the congregation and to a crisis in faith. In this situation a pastor can be tremendously helpful by reaching out to the family and by working to create an atmosphere of acceptance and hospitality within the congregation for the family and the person who is ill. A consumer describes how his priest has helped this to happen in his congregation.

St. Peter's has established a health ministry. One of the charges of the health ministry was to establish a mental health subcommittee. One of its responsibilities is to continually bring to the congregation, through the Sunday bulletins, items about mental illness. We also put books in the library and a poster about support groups on the bulletin board. We let people know that others are up front about this. So, maybe they will come out of the closet and ask for the help they need from those of us who deal with this every day.

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 remain 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.

A pastor can be very helpful in working with the family to deal with frustration, helplessness and anxiety by giving each family member a place to share his/her distress without feeling guilty or disloyal. The pastor can also be most supportive by remembering the person who is ill in the prayer life of the congregation, in keeping in contact with the person and the family, and by encouraging others to do the same. The pastor, by learning about mental illness and community resources and by making a referral, can be a catalyst for the family to learn ways to work with the person who is ill and to identify resources for their loved one and themselves

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. Members of the congregation 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

Clergy working with families should remember that often the family is the first line of defense for their ill loved one. If family members deteriorate due to stress and overwork, it can result in the ill family member having no ongoing support system. Therefore, families

must be reminded that they should keep themselves physically, mentally and spiritually healthy. Granted this can be very difficult when coping with their ill family member. However, it can be a tremendous relief for families to realize that their needs should not be ignored. There may be no one else except the pastor who will help them to focus on their needs and their concerns. The pastor should continually remind them that it is necessary to take time for themselves, despite the demands of assisting their family member. For anyone living and/or working with a person who has a mental illness, one should:

Develop Spiritual Resources: Understand that feelings of spiritual distress are a normal reaction to having a family member or friend struck by a life altering illness. Realize that other people of faith have feelings of abandonment, frustration, anger, anxiety, helplessness, isolation and hopelessness. Develop your spiritual identity and resources. Seek help from your pastor, a pastoral counselor, or a therapist who affirms the importance of spiritual resources. Continue your connectedness with your faith community.

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.

Understanding the Effect of Inappropriate Professional Assistance

Many family members have had hurtful experiences with those in the helping professions. For example, a pastor who has a son with schizophrenia had a painful experience when he led an in service training session at a mental health center. One staff member stated categorically to the group, "Families are usually sicker than the patients," (Cannon, 1990, 216). This statement was inappropriate and not based on any accepted theory of causation. When clergy, from lack of knowledge, also articulate such myths, the family quite naturally recoils. This is not atypical because for many years psychotherapy was based on the

mistaken theory that family patterns caused mental illness. One learned about poor parenting, pathological families, identified patients in the family, etc. One particularly destructive theory was that of the "schizophrenogenic" mother, and the "ineffectual" father, who both used parenting skills that caused schizophrenia in their children. None of these theories are any longer creditable. However, some are still believed by people who have not kept abreast of advances in the field over the last twenty-five years. The dynamics of what happens in the family when a member is struck with any life altering illness, including mental illness, are important. Mental health professionals and support and advocacy groups have a variety of tools to use to assist the family in dealing with what has happened. Referring a family to a mental health professional and a support and advocacy group can be very beneficial to them in learning about mental illness and how to assist the person who is ill and themselves in managing it.

Facilitating a Referral

Getting the family to a helping professional or organization is of little value if they arrive too angry, confused or defensive to be able to listen or be helped. Family members who accept the referral out of compliance, or simply to please the pastor, other family members or friends, may still be closed to any assistance.

The minister must first foster an open and trusting relationship. Family members should be encouraged to share their feelings about the proposed referral. Objections and any feelings of rejections can then be identified. The pastor should make clear why the referral is being made. And the pastor should emphasize that he/she will continue to give spiritual support and guidance.

The goal of the referral is not to force an unwilling person(s) to spend a few minutes with someone who has expertise. The goal is to help the person(s) visit an additional source of information and resources with openness and hopefulness.

Dealing with Objections

The family may be unwilling to accept the referral because of receiving inappropriate advice in the past. Listening to the family's prior experiences, if there are any, with the mental health system can help clarify objections and make it possible to work around them. Acknowledge the pain and frustration this may have caused. But also acknowledge that a pastor does not have all the technical answers the family may require or the skills to assist them in working out some of the problems the family may be experiencing and that is why they are being referred to other resources.

Reassurance of Continuity

Reassure the family that this referral is not a rejection. The pastor will continue to be there to assist the family with theological and spiritual issues and to hear of any problems that they have encountered with other resources. Affirm that the church is a place that will always be there to be with the family as they work through their individual spiritual journeys. Encourage family members to give feedback about the receptivity and usefulness of the person, agency or support group. In this way everyone concerned will be able to evaluate if the referral has been helpful. If it is not, assist the family to find more appropriate resources. How

Mental Health Resources Can Assist a Family

Mental health professionals and support and advocacy groups help a family as they work through their feelings of loss, confusion, and concerns about caring for the ill family member. They can provide information about:

- a. the illness, symptoms, prospects for recovery and suggestions on helping to manage symptomatic behavior
- b. how the brain is affected
- c. medications, side effects and how the medication interacts with other medications
- d. written materials, references, sharing, expertise in problem solving, communication and resources
- e. educational opportunities, such as workshops or lectures
- f. planning for the future in terms of finances, housing, rehabilitation, etc.

Mental health professionals use a number of approaches in working with families. One is *Family Systems Theory*. Murray Bowen, M.D. did the seminal work in this area. Systems theory can help people understand what is happening to them both historically and environmentally. Family systems look at patterns of behavior in the context of the family, assessing both its strengths and weaknesses. Family system theory enables all members of the family to understand and develop ways of assisting and supporting each other. Family systems have been applied to a wide range of issues. For example, Edwin H. Friedman in his book, *Generation to Generation: Family Process in Church and Synagogue*, applied family systems theory in understanding the dynamics of congregational life. Necessity to Assess Treatment Choices and Family Resources

*This section is based on information from **Coping with Mental Illness in the Family: a Family Guide** by Agnes B. Hatfield, Ph.D., which is a National Alliance for the Mentally Ill (NAMI) Publication. It is an excellent resource for families who should contact their local NAMI affiliate to check it out of their library or purchase it from the national office.*

About a fourth of the people who have a mental illness will have a single episode. About three fourths will continue to have various degrees of symptoms over time. This seems to be true no matter where or how they are treated. Since treatment and care is costly, it is necessary to plan for the future. Families who have lived with mental illness for a long time often describe how, at the time of the first episode, they sometimes commit themselves to very expensive treatment in expectation of a cure that never materialized. Eventually they found themselves providing for long term care with severely drained resources.

Before making commitments to any treatment, families should consider:

- a. How much insurance coverage does the ill person have, should the illness be long-term? What is the best plan to assure benefits are available for the required time?
- b. If other financial resources are available to the family, how much should, in all fairness, be reserved for the needs of all the members of the family for education, health care, and

retirement options? These are hard choices, but they must be made or there are regrets later.

c. If a family is considering a particular type of treatment, they should fully explore to what extent research can demonstrate a positive outcome. They should not be swayed by the enthusiasm of those who provide the treatment.

d. Families should know that the costliest care is not always the best. Money will not cure mental illness. Private care is not necessarily better than public. There are real limits to the effectiveness of any treatment. Many people will continue to need medication. Others may need medication and ongoing assistance with social and vocational skills. Beyond that there is no magic that can erase all the effects of mental illness.

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