

WATER FROM THE ROCK: LIVING WITH SERIOUS MENTAL ILLNESS IN THE FAMILY

PENELOPE A. FRESE, PH.D.*

I. INTRODUCTION

Whatever is human concerns the law. This Article arises in experiences outside the law with the hope of bringing greater clarity and understanding to those areas where the law is not clear and there is some room for flexibility. The *National Symposium on Mental Illness and the Criminal Justice System* invited me, as a member in a household where there is mental illness, to elaborate on the impact that mental illness has on family life. My husband, a practicing psychologist, was diagnosed with schizophrenia at the age of twenty five. Our four children have all been diagnosed with major depression. All continue to take medication for their illnesses, and they occasionally experience symptoms. Unless one has been there, it can be difficult to understand how insidious these illnesses are and how pervasive their influence on all aspects of daily living. Mental illness can be tremendously disruptive to normal family functioning, and, especially when untreated, it can throw families into turmoil that sometimes brings them into the criminal justice system. Persons who require hospital care find themselves in jail. This Article will outline aspects of recognizing and dealing with mental illness within the family with the hope of providing some insight and direction for those who provide for such individuals.

II. DENIAL

My husband, in his article on coping,¹ explains that for the person with the illness, the part of the brain that would tell him he is sick is the very part of the brain that is impaired. It is therefore very difficult for persons

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* Dr. Penny Frese has a Ph.D. in Comparative Arts and an M.F.A. in Directing from Ohio University. With her husband and children, she is active in the mental health movement, often presenting at statewide and national conferences in the United States and Canada. The Frese family has been featured on local and national television, including pieces on CNN and ABC. Dr. Frese is also the producer of an award winning video on children's depression called *Claire's Story*.

¹ Frese, F. J., *Twelve Aspects of Coping for Persons with Schizophrenia*. 2 INNOVATIONS & RESEARCH 39-46 (1994), available at <http://www.fredfrese.com/copingskills.html> (last visited Feb. 15, 2004).

with mental illnesses to know they are ill. For others, stigma, shame, and fear contribute to the difficulty of acknowledging that there is mental illness in the family. Mental illness has been traditionally regarded as a character flaw or the result of family dysfunction. Families fear that acknowledging that a family member has a mental illness will invite unfavorable attitudes towards them, resulting in ostracism or criticism. They are afraid that one family member with a mental illness can bring opprobrium down on them when they know that other family members under similar circumstances show no evidence of illness. They know, and rightly so, that the responsibility for difficult behavior by their ill family member is not their fault, and they resent the implication, tacit or otherwise, that it is.

As with other illnesses, when the ill family member is unable to care for himself, responsibility for his care frequently falls to his closest relatives. But treatment for mental illnesses is difficult to access, time consuming, lengthy, and, very often, expensive. Memories of days when the mentally ill were locked away in institutions still prevail. Many people don't even know where to begin. So instead of getting help, the illness is denied. The ill person is treated by family and society alike as if his behavior is deliberate and controllable. The result is condemnation, frustration, resentment, anger, and ultimately exacerbation of the condition to the point where some other entity must step in. Often this is the criminal justice system, and frequently, even here, real help is not available. The fear, shame, and frustration that families experience become self-fulfilling prophecies. Untreated mental illnesses do contribute to family dysfunction, ostracism, and criminal behavior.

Denial gives way to acceptance when no other recourse is available. However, there is much more we can do to accelerate the process. The earlier we deal with mental illness, as with any illness, the better the prognosis. Research in the last fifteen or so years has resulted in vastly improved medications and other treatment modalities which not only improve situations, but can actually restore even severely mentally-ill individuals and allow them to become contributing members of society. In the remainder of this Article, I will examine the three A's of the coping process for families.

III. ACCEPTANCE

Acceptance generally comes gradually, but it can be accelerated. The first stage of acceptance comes with the understanding that what we are dealing with is an illness; that it is long term; and that things will not get better until steps are taken to begin that process. I refer to this type of acceptance with a small "a." It is important in this stage to increase knowledge about mental illness.

When I first started to learn about mental illness about 25 years ago, there was very little information available. Most of it was dry, clinical, and

hopeless. Today, however, there is a rich body of literature, both clinical and personal, much of it designed for the layman. From it, we can learn that these illnesses are, indeed, physical. Various magnetic imaging techniques have allowed us to actually see a working brain, and have demonstrated that the brains of persons suffering from mental illnesses function differently than the brains of those who are not so afflicted. Understanding these conditions as illnesses does much to relieve the guilt and blame which many family members feel and which can prevent them from taking the steps necessary to address the problem.

Understanding that these illnesses are brain related, however, is only the first step. Although the past decade has seen marvelous improvement in the understanding and treatment of mental illnesses, the surgeon general² and the President's New Freedom Commission on Mental Health³ both acknowledge a treatment system that is fractious, inefficient, unreliable, and difficult to access and navigate. In short, it is deplorable. Family members and consumers of mental health services often need help in understanding what treatment consists of and how to get it. This is where support groups such as the National Alliance for the Mentally Ill (NAMI) can be especially helpful. NAMI has a twelve-week program for families called *Family to Family* taught by family members who must also deal with the mental health system. In it, family members can learn about these illnesses, their symptoms, treatment modalities, medications and their side effects, accessing and working with treatment professionals, and coping skills. As NAMI operates through local affiliates, those offering the course also have first-hand knowledge of their own geographic areas and helpful providers and agencies, and they can offer support for the anxieties and frustrations that people accessing the system often experience. Many hospitals, clinics, agencies, and other non-profits offer similar seminars that can be very beneficial to consumers and their family members in raising awareness of the illness and dealing with it.

Acceptance with a capital "A" comes when one can accept the person with the illness and recognize that it is a part of who they are, that it is manageable, and that it often brings its own gifts. When that happens, we cease to fight the illness and we begin to work with it. Studies such as Kay

² U.S. Department of Health and Human Services, *Mental Health: A Report of the Surgeon General*, U.S. PUBLIC HEALTH SERVICE (1999), available at <http://profiles.nlm.nih.gov/NN/B/C/X/C>.

³ The final report of the New Freedom Commission is available online at <http://www.mentalhealthcommission.gov/reports/FinalReport/FullReport.htm>. The section entitled "The Current Mental Health System Is Complex" enumerates the difficulties consumers must face when trying to deal with their illnesses.

Jamison's *Touched by Fire*,⁴ and work by Michael Schwartz⁵ in Cleveland and by Manfred Spitzer of Ulm, Germany,⁶ is demonstrating that persons with mental illnesses are often also extraordinarily gifted. The NAMI poster, "People With Mental Illness Enrich Our Lives," lists Abraham Lincoln, Virginia Woolf, Lionel Aldridge, Eugene O'Neill, Beethoven, Donizetti, Robert Schumann, Leo Tolstoy, Vaslov Najinsky, John Keats, Tennessee Williams, Vincent Van Gogh, Isaac Newton, Ernest Hemingway, Sylvia Plath, Michelangelo, Winston Churchill, Vivien Leigh, Jimmy Piersall, Patty Duke, and Charles Dickens, all of whom suffered from mental illnesses. Some, like Lincoln or Churchill, continued to live productive public lives. Others, such as Plath or Woolf, needed to take occasional time off to heal. Van Gogh needed the continued support of the mental hospital at Saint-Remy in order to function. No one would debate, however, the very real, substantive contributions made to their own times and to humanity.

Of course, most persons with mental illnesses are not able to make such outstanding contributions, but these remarkable persons teach us to look for each individual's gifts and to try to assist them to build on their strengths rather than condemning them for their weaknesses. Personal accounts by people with mental illnesses⁷ also help us to increase our appreciation for the daily courage that is required of disabled people. Acceptance with a capital "A" allows us to listen with compassion, grieve the losses, and celebrate the triumphs of persons with mental illnesses. We get into their skin, as it were, rather than trying to "fix" them or make them like us.

However, this full acceptance comes with some caveats. First, violent or abusive behavior is never acceptable, even if it is related to the illness. In circumstances where there is a proclivity to violence or abuse, advance directives can be very helpful in preventing undesirable outcomes while permitting the consumer to remain in control of his own life. Mary Ellen Copeland's work on preventing relapse⁸ is especially helpful in this area. Second, mental illnesses, except in extreme cases of prolonged severity, do

⁴ See K.R. JAMISON, *TOUCHED WITH FIRE: MANIC-DEPRESSIVE ILLNESS AND THE ARTISTIC TEMPERAMENT* (1993).

⁵ Dr. Michael Schwartz heads The Irwin Foundation, which targets the aspect of recovery from mental illness.

⁶ See M. SPITZER, *THE MIND WITHIN THE NET: MODELS OF LEARNING, THINKING AND ACTING* (1999).

⁷ See K.R. JAMISON, *AN UNQUIET MIND: A MEMOIR OF MOODS AND MADNESS* (1995); CAROL NORTH, *WELCOME SILENCE: MY TRIUMPH OVER SCHIZOPHRENIA* (1990); and LAUREN SLATER, *WELCOME TO MY COUNTRY* (1996).

⁸ MARY ELLEN COPELAND, *WINNING AGAINST RELAPSE: A WORKBOOK OF ACTION PLANS FOR RECURRING HEALTH AND EMOTIONAL PROBLEMS* 43-66 (1998).

not excuse persons from accepting responsibility for their own lives. Despite illness, one still has the obligation of finding one's own happiness and fulfillment, and of being a contributing member of society. That responsibility cannot be dismissed or assumed by another. I have tried to instill in my own children this sense of responsibility. I tell them that these disorders are unfortunate. These disorders may be the reason that achieving success in their lives may be more difficult for them than for others. But they are never an excuse. In planning for themselves, they must always take into account the realities of their lives, including their disabilities, and make provisions for them. This in no way implies that persons with mental illnesses cannot achieve or should lower their standards. History is full of examples of those who have succeeded despite seemingly overwhelming adversity. It simply means that, ultimately, it is up to them. While I cannot and will not assume responsibility for my children's lives, I will be a companion to them on their difficult journey and supply what encouragement and assistance I can. I will assure them that they already possess all that they need to succeed.

IV. ACCOMMODATION

Accommodation is the name of the game. It is the direct application of that human trait that has allowed the species to survive and dominate the earth. The adage, "If the door is locked, go in the window," sums up the accommodation attitude. With astonishing variety, human beings have demonstrated that they can find the means to overcome almost any barrier.

One must not assume, however, that accommodation falls totally to the consumer. To effectively deal with mental illnesses, accommodation must occur on both sides of the fence; that is, both those who are ill and those who are not must adapt. There are some aspects of mental illness that, while they may be disconcerting to those not afflicted, are not really harmful. Someone walking down the street mumbling to himself might cause some level of discomfort in others who are unsure if they are being addressed, but such behavior really does no harm. When we understand that such behaviors can be a consequence of mental illness and pose no threat, we can easily adjust our response to ignore or casually accept the behavior. I am reminded of an instance that occurred in our home one afternoon after school. I was grading papers and our youngest daughter, Bridget, was doing homework. Another daughter, Claire, was somewhat manic that day. She leapt into the room wearing a towel as a cape around her neck, laughing and shouting with great silliness. Bridget and I looked up, smiled, and then continued with our work. Claire stopped for a moment, looked around the room, and then said, "I love my family. In other families that might have occasioned comment."

However, to be able to ignore or accept harmless behaviors, one must be able to recognize that they *are* harmless. The first step in accommodation is learning to recognize symptoms. This requires careful

observation, some knowledge of symptomology from a reference such as DSM-IV,⁹ and open discussion with the consumer. In the early days of our marriage I was distressed that my husband would look away when I spoke to him. I interpreted this as disinterest in what I had to say. One day I deliberately threw in non-sequiturs to prove that I was right. He stopped me and very gently explained that he was listening, but that he was very sensitive to visual stimulation and found that if he looked at a neutral visual field, he could better concentrate on what I had to say. While I was aware that failure to make eye contact was a symptom of mental illness, I never understood why until that day.

Once symptoms are isolated, one can begin to work on them. Naturally, one wants to prioritize those symptoms which most significantly interfere with the ability to function. These will differ from consumer to consumer. Persons able to work but without access to transportation may need help to resolve that issue. Children subject to explosive outbursts need to find acceptable ways to vent their frustrations. Consumers who are especially sensitive to noise or movement may need more isolated cubicles or separate offices. Who needs to make the accommodation—consumer, non-consumer, or both—will vary depending on the circumstances. What is important is the willingness and commitment on both sides to find the way to make situations work.

While specific accommodations vary from consumer to consumer, there are a couple of accommodations which may prove helpful in general. The first has to do with sleep. Sleep presents problems in a broad range of illnesses. Persons with depression often cannot fall asleep or stay sleep and have trouble waking up. No matter how much sleep they get, they don't feel rested. Days and nights get turned around, and sleep deprivation can trigger or aggravate symptoms. We have found that finding someplace to go that is quiet and restful can be very helpful. Rather than trying, Rambo-like, to drive ourselves through difficult situations, we do better when we can back off, rest, and face problems refreshed.

Another area of concern is what treatment professionals refer to as "high EE," or expressed emotion. Persons with serious mental illnesses are often exquisitely sensitive to criticism and perceived criticism. Some studies have shown that persons released from the hospital into situations where there is negative criticism and over-control are more likely to relapse than if they went off medications.¹¹ The reverse of this may also be true. Persons whose egos have been beaten up by mental illnesses require higher instances of assurance and encouragement. There are many ways to do this. The refrigerator is a good place to put up continual reminders of past successes. When good grades, notes of thanks, mention in the

⁹ AMERICAN PSYCHIATRIC ASSOCIATION, DIAGNOSTIC CRITERIA DSM-IV 1995, available at <http://www.appi.org/book.cfm?id=2027>.

newspaper, or complimentary pictures are hung there, the consumer and everyone else in the family is reminded of his good qualities every time they pass that way. We try to make a mantra of "Find the good. Praise it." Once we start looking for opportunities for genuine compliments, we generally will not have a hard time finding them. For some consumers, even getting up is a heroic effort. Good grooming habits, controlling impulses, facing difficult situations, thinking of others, persisting in tedious work, rephrasing negative comments—all these deserve our praise, and the list goes on and on. When criticism is necessary, it can be couched between positive and reassuring comments. Shouting, sarcasm, or the pressure of responding to the demand for explanations can be paralyzing for persons with poor verbalization skills who are easily overwhelmed. Even exuberance in joyful situations can be over stimulating. Quiet, even communication is generally best. On the consumer's part, learning to back off from stressful situations is a good habit to develop.

Accommodations are easy to find when one is in the habit of considering all of the options. Whenever a problem comes up, frustrations and feelings of hopelessness can be diverted into the more positive task of examining options. One option, of course, is to do nothing and leave things as they are. But, generally, as we begin to consider other ways of approaching the problem, solutions begin to appear possible.

As one gets into the habit of finding accommodations, most problems begin to appear resolvable. However, while this may be true, it is equally true that overcoming disabilities requires an enormous amount of energy, and sometimes the end result is not worth the effort. The consumer himself should have the last word on what issues most demand resolution. However, the general principles guiding the work of accommodation is to build on strengths already present and to develop necessary skills that allow the consumer to function at a level allowing for both a contribution to society and personal satisfaction.

V. ADVOCACY

Advocacy is the queen of the process. I used to think that advocacy meant doing more, and as a wife and mother in a household where multiple members were disabled, the idea of trying to do more was overwhelming. I now know, however, that advocacy does not necessarily mean doing more; it means doing differently. As I watched my young children correct their friends on the playground when they heard derogatory terms about the mentally ill, I realized that they were practicing advocacy. Whenever we disseminate correct information about mental illness, treat the mentally ill with respect and compassion, refuse to participate in ridicule of mental illness, and turn in disgust from those who do, we are advocates. When we support equal opportunity for those with mental illnesses, vote in favor of mental health levies, and demand equal insurance coverage, we are advocates. Advocacy does not demand that we take dangerous stances or

risk our money, reputation, or social standing; it asks only that we work quietly among those we know in the daily circumstances of our lives. That is enough. For those whose lives have been bruised or broken by mental illness, advocacy heals.

As my children advocated among their peers, and then in other public situations, I saw them mature. As Claire put it after an interview for a magazine, “If I am going to talk to others about managing mental illness, I had better be managing it.” As they advocated, they grew in confidence and found their own voices. It is difficult to argue with one who has been there. For those who have lost loved ones to suicide, or portions of their lives to madness or addiction, advocacy gives meaning and validity to their pain. They are able to bring something positive out of tragedy. Advocacy is a blessing for those who give and those who receive.

What about those who are not ready for our advocacy, those who can’t be bothered, who are too busy, entrenched in their own ways, understaffed, underfunded, undereducated? Generally, I advocate the small dog approach—bite the ankle. Hold on. Time and justice are on our side. At the *National Symposium on Mental Illness and Criminal Justice*, however, one of the judges took me aside and said, “We are the big dogs.” I am used to speaking before those who are powerless beyond the force of their own just cause. But the law, and those who administer it, possess a tremendous power for change, and with that power comes a grave responsibility. This conference has been a promising step in the exercise of that responsibility.