WALKING ON EGGSHELLS:

A Resource Book for Families Facing
The Challenge of Major Mental Illness

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Introduction

"While the family may not cause mental illness, it may be one of the most powerful factors affecting the outcome"

Herbert Gravitz, The Binds that tie-and heal: how families cope with mental illness", Psychology Today, March 2001.

This book is written for family members of consumers (or persons diagnosed) with one of three major mental illnesses: Depression, Schizophrenia or Bipolar Disorder. We have organized this book around four important tasks for family members: **UNDERSTANDING, CARING, HELPING AND ADJUSTING.**

UNDERSTANDING.

First, you must gain knowledge about your relative's diagnosis. In this resource book we have elected to focus on three major mental illnesses: depression, bipolar illness, and schizophrenia. In addition, we present information on three serious problems: suicide, first-episode psychosis and substance abuse. We begin each UNDERSTANDING chapter with personal accounts and experiences of consumers or family members who tell their personal stories in the hope of offering you some insight into their actual experiences, along with some personal advice. Next, professional contributors provide the most recent information about the specific diagnoses and treatments. The current diagnostic system for all mental disorders in the United States is the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV). The DSM-IV classifies mental disorders based on the presence of certain specific symptoms, how long they have been present and how disruptive they are, and the absence of evidence for other causes of the symptoms (e.g. brain tumors or severe metabolic disorders). An increasing body of clinical research has advanced our understanding of the theoretical basis and underlying causes of these major mental illnesses and has refined our knowledge of brain function and the mechanism of action of antidepressant, antimanic and antipsychotic medications. In this book, we have not elaborated on drug information because it is continually updated. However, we strongly encourage you to have active discussions with prescribing physicians or pharmacists for complete and up-to-date information on prescribed medications. The web sites listed in our Resource Appendix are also helpful sources for medication information.

CARING

Secondly, you must understand and manage your personal reactions so that you are better able to help your mentally consumer. In our CARING chapters, we focus on the typical and atypical reactions of concerned family members. In Chapter 8 we focus more generally on the reactions and experiences of the entire family unit. For example, when family members realize that the mental illness is not the result of someone's failings, but it is a legitimate illness that can be treated, many of their negative thoughts and fears disappear and they can move forward. In Chapter 9 we focus specifically on the primary caregiver, defined as the person who assumes most of the responsibility for the day-to-day care and supervision of the consumer. In Chapter 10 we discuss the important issue of psychiatric stigma because there is now growing awareness that both consumers and families of the mentally ill are stigmatized.

HELPING.

Your third challenge involves assisting your mentally consumer in finding good treatment and supportive services in their community. The treatments discovered in the past 50 years have had a tremendously beneficial impact on millions of people suffering from these devastating conditions. Further, as our knowledge continues to grow, new treatments are being explored every day. As the rapid pace of discovery continues, the future for the development of more effective and rapidly acting treatment seems bright. In this section, professional contributors describe several treatment or service options within health care systems and within the community. The most popular national and regional resources are described briefly in our Appendix. Lastly, services are highly dependent on payment plans so we discuss two of the more prominent payment plans that cover the mental health care for many persons with serious mental illness: Managed Care and Medicaid.

ADJUSTING

Lastly, you must learn to cope with the reality of major mental illness and the problems that arise during its course. ADJUSTING begins with a chapter dedicated to the important issue of medication adherence, which is defined as staying on a prescribed medication regimen. We dedicated a whole chapter to this subject because our families asked for it; they cited medication adherence as their most serious issue. Next, family members of our local support group meetings offer very practical advice and guidance. In the final chapter of this section, we focus on the unique needs and concerns of parents with a mentally ill child or adolescent. Because this resource book does not focus specifically major mental illnesses that develop in childhood or adolescence, we encourage readers to use the web sites and listed references in our Appendix.

Part I

UNDERSTANDING

1

DEPRESSION

MYSELF

I have come to the realization that my life changes had made me depressed. I hadn't dealt with them. I had just moved on and did not really deal with the situations that made me depressed. Until it all came to a head.

I had gotten divorced from an abusive marriage. I didn't have time to deal with that so much, because I had to raise my children. I had to move on from that situation. At the same time, I lost my long-time job. I lost my house. And, all the while, I still had to worry about the kids and making it from day to day. That was a very stressful time for me, but I still didn't deal with it.

What brought it to a head was my getting sick—getting a cancer diagnosis. After the cancer diagnosis and chemotherapy, everything was okay. But, I still felt terrible. And, I just could not pull out of it. This was a time in my life when I had a chance to reflect on everything that occurred over the last fifteen years. We (my doctor and I) came up with the realization that I had been depressed for the last fifteen years and I had never dealt with it. I had just gone on day by day, feeling rotten. I hated to get up in the morning. I woke up with a feeling of dread about what kind of day I was going to have; just not looking forward to a lot of things. The cancer diagnosis was just a small part of that because, for that (the cancer diagnosis), I grieved. I think everyone grieves when you go through a cancer diagnosis, but you live with it. It was the other changes that caused the depression.

No one really helped me when I first became depressed. My children didn't understand, but they were young and into their own thing. But, as I got older, and even when I got the cancer diagnosis, they still didn't understand. I basically dealt with the depression on my own. Then I heard about a depression study on the radio. And, I knew that something wasn't quite right when I could not pull out of the depression. I then decided to see about the study.

A year and one-half ago, I started with the clinical study, and I started on several medications. Then I started to feel better. I started to deal better with my life and the circumstances of my life.

I started to make decisions. I started to fight back; I did not let people take advantage of me. I started making demands on things that I should have made demands on a long time ago-what would make me happy. I started thinking about myself and the things that I could do to improve my quality of life. I made a lot of changes.

After I lost my house, I had moved in with my father and my mother. I had been there for more than ten years. My whole life was never an ideal situation for any child to be raised. My father was an alcoholic; my mother was submissive to any verbal abuse that he put on anybody. That was not an ideal situation in which to raise my children, but I thought I had no other choice. But, I really had a choice all along; I just didn't act on it. I moved out of the house with my mother. I started making changes to my life and I feel a lot better. I started making demands on what I expected of my children. They have gotten older, and I am not responsible for their happiness. They have to do for themselves. I have done everything that I can possible do for them. But, it's still not enough to them, so I have to cut that off.

And I've just started to focus on myself; what makes me happy. I was going to art classes.

The best advice I would give to someone who feels that they are depressed is to encourage them to get help. Other people should not be critical. People kept telling me to "snap out of it" and saying that to someone who is depressed is not helpful. Sometimes, the depressed person need to get help to get out of their depression on their own. With depression, you suppress a lot of emotions and try not to let things affect you. But, that's what makes you depressed.

I haven't had any trouble with the medications-no side effects. Just some stomach upset at the beginning, but no terrible side effects. And, I've never been suicidal. As rotten as my life has been, I've never been suicidal. I think that probably what has kept me going is that I have a strong will. It's important for me to live. I continue to make changes in my life. I continue to talk to my children, because they are still in denial!

Ten years ago I wrote this paper, entitled "Reclaiming My Life" that I would like to share with you:

RECLAIMING MY LIFE

> Ever since I was a little girl, I have been looking for that family unit. My father was what is known as a functioning alcoholic, my mother the enabler. Our appearance to the outside was a middle class black family with a happy and

secure home life. On the inside, my sister and I went through a life of torment. As children, we could not understand why our father did not like us and could not stand to be around us. It was even harder to understand why my mother stayed married to him.

When my father was drinking, usually on weekends, he would verbally and, sometimes, physically abuse all of us. When he was sober, he became reclusive to us; never carrying on a conversation with us or acknowledging our existence.

My mother, on the other hand, tried to overcompensate for his deficiencies and she would make excuses for him. When it came to him telling my sister and me how no good we were, she never stood up for us.

Now that I am 38 years old and looking back on this, I just feel sad; sad for the childhood that my sister and I never had and even sadder for my mother because she could not figure her way out of this mess. I have also realized through a lot of reading and soul searching that it did not start with my parents. We were brought up in what is now called a dysfunctional family. I mean grandparents, aunts, uncles, etc. We are the sum total of all of these people.

From the age of 18 to 38, I have been looking for the love and sense of family I have never had. I have had two bad marriages that were almost a mirror of my mother’s life with my father. After my second divorce, I said to myself “There is something wrong with me.” “My life is not working.” I went to a therapist, who to me, was a Godsend.

In essence, what the therapist told me was that I had become so accustomed to thinking that I did not deserve good things to happen to me that I did not seek out positive soul mates, only negative characters. My life had become a series of events that directly related to my childhood. I had to learn to love and accept myself for the person I am and when I finally accomplished that, I found peace and joy that is beyond anything that I have ever known.

I have also learned to forgive my parents because, in a way, they were also victims. Children learn what they live and we are all mirrors of our parents. In order for us to break the cycle of abuse, we have to first recognize there is a problem. We have to ask ourselves this question: Are we happy, content and at peace with ourselves? Finally, I can say yes! I do not have to have a husband or lover to justify my existence. When they come into my life, they are just extras because I am a whole person by myself. A person of worth, and I do not have to compromise my happiness and

> peace of mind for any one. For once in my life I am in control of my destiny.
>
> My father has cancer now and I am dealing with that in my own way. Through my conversations with my mother, I have learned a lot about her feeling and about our lives. I explained to her that I cannot feel any differently about my father than I always have because the emotions are just not there. I love him, but there will always be a void emotionally because I never knew him; he would never let us get close to him. I just hope somehow he finds peace within himself, because we can never go back and reclaim that past and change it. We can only go forward and claim our lives and happiness today.

Overview

It is currently believed that mood disorders are caused by a complex interaction between biological risk factors that make certain people more vulnerable than others, stressful life events and traumatic life experiences, a person's coping abilities, and a persons physical health and general medical status. The most likely person to develop depression is someone with a family history of severe depression, lives with severe stress and has had many traumatic life experiences, has a chronic general medical illness (such as diabetes), and has poor coping strategies. In other words, this person tends to makes things worse for themselves when under stress. Therefore, most people have both stressful life events and biological causes for their depression.

When someone is in a depressive episode, it is often said that they have a chemical imbalance. It is important to understand that this imbalance does not simply happen on it's own in most people. Rather, having stressful life circumstances, severe medical illness, or very poor coping strategies can trigger it.

Diagnosis

In our introduction, we described that psychiatrists in the United States use the Diagnostic and Statistical Manual, Version IV, to make a diagnosis. We provide the DSM-IV Criteria for Major Depressive Episode:

A. **Five (or more) of the following symptoms have been present during the same 2-week period and represent a change from previous functioning; at least one of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure.**

1. depressed mood most of the day, nearly every day, as indicated by either subjective report or observation made by others.
2. markedly diminished interest or pleasure in all, or almost all, activities most of the day, nearly every day (as indicated either by subjective account or observation made by others)
3. significant weight loss or weight gain when not dieting, or decrease or increase in appetite nearly every day.
4. insomnia or hypersomnia nearly every day
5. psychomotor agitation or retardation nearly every day (observable by others, mot merely subjective feelings of restlessness or being slowed down)
6. fatigue or loss of energy nearly every day
7. feelings of worthlessness or excessive or inappropriate guilt (which may be delusional) nearly every day (not merely self reproach or guilt about being sick)
8. diminished ability to think or concentrate, or indecisiveness, nearly every day (either by subjective account or as observed by others)
9. recurrent thoughts of death (not just fear of dying), recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.

Major Depressive Episodes can further be described in regard to whether the person also has symptoms of psychosis. These symptoms include patently false beliefs (called delusions) or auditory hallucinations (hearing voices when no one is there) or visual hallucinations (seeing things that are not there). The delusions or hallucinations invariably have a depressive content. For example, a depressed and psychotic person might believe that they have an incurable illness because God is punishing them for being a bad person. Recognizing psychosis is very important because it reflects a more severe form of a mood disorder, frequently requires different treatments, and is more often associated with potentially dangerous behavior or suicide.

Prognosis

According to a landmark study published in 1994 called the National Comorbidity Study (NCS), Major Depression is the most common of all mental disorders, with approximately 17% of adults in the United States experiencing an episode of Major Depression in their lifetime. With the current population of the United States, this would amount to approximately 19 million adults suffering from an episode of depression during any single year. The majority of consumers with a mood disorder will have more than one episode. Recurrence rates for depression are estimated to be at least 50% for consumers with one episode of Major Depression and 80 to 90% if the person has had two episodes.

Treatment

Depression is frequently undertreated. Most individuals with depression obtain their treatment in physician offices. The most comprehensive study to evaluate the treatment of depression in physician offices was the Medical Outcomes Study by Dr. Ken Wells. Seventy-eight percent (78%) of the consumers with Major Depression were receiving no antidepressant medication at all and 19% were only receiving a minor tranquilizer.

In 1993, a document was produced by the Agency for Health Care Policy and Research called the Depression Guideline Panel. The acute treatment phase begins with a clinical interview, diagnostic assessment, physical and neurological examination and clinical and laboratory studies as appropriate. The goals of this phase include establishing a diagnosis, defining a short-term and long-term multidisciplinary treatment plan, selecting the most appropriate medication and finding the right dosage, monitoring of side effects, and monitoring response.

Medications restore function but the disease process is not cured. A large number of factors can influence the physician's selection of antidepressant drug and therefore the choice should be made on an individual basis. Antidepressant medications are usually indicated for Major Depression. Several situations call for initiation of medication treatment as soon as possible. These include conditions where improvement is unlikely without medication treatment, where possible harmful consequences may arise if the depression is untreated (e.g.. loss of job or risk of suicide), or where relapse and recurrence are highly likely outcomes. Other situations where medication treatment should be initiated include consumers with a strong family history of mood disorders or in those consumers with Major Depression with atypical features.

Medication treatment should be postponed if the diagnosis of Major Depression is unclear, the symptoms very mild, the risk of harmful consequences minimal, or if the consumer is strongly averse to the use of medication treatment. The most common of these situations occur when a recent life stress raises the possibility that the presenting symptoms represent a moderate to severe form of an adjustment disorder or that the depression may be secondary to medical illness, use of other medication or substance abuse. The decision to initiate medication treatment in these cases should follow one or two further evaluation meetings.

The acute treatment phase lasts from 6 to 12 weeks and consumers are usually seen every 1 to 2 weeks during this phase. Discontinuation of medication during or before this phase is complete is associated with a high rate of relapse. Relapse involves the return of some symptoms of a disease during or on cessation of treatment.

Continuation treatment lasts four to nine months and can be thought of as a consolidation phase. A recent World Health Organization (WHO) consensus meeting suggests that the minimum period of time for continuation treatment is six months.

Maintenance is in general thought to be prophylactic, although it is increasingly clear that for many consumers this phase is essential, not simply to prevent new episodes but to maintain the response, since the illness persists. Newer data suggest that medication dosing during the maintenance phase should continue at the same level as during the acute phase and that supportive psychotherapy can help to reduce the rate of relapse and recurrence.

Recovery involves a more complete remission, implying the absence or near absence of symptoms. Consumers should be seen every four to 12 weeks for the first year of maintenance treatment and at six month to yearly intervals thereafter. The frequency of visits during this phase should be individualized based on psychosocial factors, compliance and presence of symptoms and side effects. Rates of depressive relapse appear to be higher when antidepressant drugs are discontinued rapidly compared to a slow (three to four weeks) taper. Therefore, if an antidepressant is discontinued, it should be tapered over at least a four-week period.

2

BIPOLAR DISORDER

MYSELF

A psychiatrist first diagnosed me as bipolar in 1972. At the time, I was having job problems and was anxious about a probable strike at the manufacturing company at which I was General Manager. When my psychiatrist died a few years later, I went through 8 or 10 psychiatrists plus two psychologists. I continued to experience highs and lows, exacerbated by mild alcohol dependency that sapped my energy, reduced my appetite and, together with the bipolar thing, caused sleep disorders. Drug therapy was ineffective; starting with lithium carbonate, going through all the tri-cyclics known to the pharmaceutical industry, and ending up with Prozac and Wellbutrin. A lot of dollars spent on drugs and psychiatrists' time, for the most part to no avail.

I am an engineer by training - taught to analyze problems and take corrective action. I also have a layman's interest in medicine and psychology so I did a lot of self-evaluation and self-diagnosis/treatment [a risky thing to do]. Here were six questions I tackled on and off for the better part of 30 years:

- What triggers the onset of a "low"? My lows typically take about two weeks to develop from the first 'blue feelings' to total depression.
- What 'snaps me out' of lows? As a rule, the recovery is precipitous and dramatic. It's like flipping on a light switch. Sometimes it's a dream that I wake up from feeling 'ok'. Other times it's by using prayer and the Alcoholic Anonymous (AA) 12 Step approach. Sometime by an unexpected phone call from a friend or relative.
- Why do I lose interest in everything I normally take pleasure in, music (playing the piano, listening to CD's, etc.) and including people? I get to the point where I won't accept phone calls, even from my best friends and family.
- Why can't I have "fun" when fun situations develop? Why don't I want to have fun? Why do I envy total strangers I observe laughing and having a good time?
- Why do I stop watching TV except for occasionally re-watching something that I've seen before rather than searching for a new program/series?
- Although I don't feel sorry for myself, why do I feel

worthless, helpless, incapable of doing anything - even things I normally enjoy doing. I guess the clinical term is ‘self-loathing’?

I could go on. However, the following is what I’ve concluded, right or wrong: It’s a sense of ‘worthlessness’, undeserving of enjoying life because I’ve let so many folks down, including myself. I feel I haven’t earned the right to have pleasure, since I can’t seem to get myself to accomplish even the simplest tasks. Usually when I’m “on the beam”, as my mother used to say, I over-commit and by so doing, build failure into my life thereby creating expectations that are unattainable. Along the way, I wear myself down trying to do too much and by keeping busy constantly. Finally, I run away from the problems I’ve created rather than facing them and telling folks I’ve agreed to do things for that I have to reschedule my workload and negotiate new deadlines.

My conclusion, then, is that bipolar behavior is just an exaggerated form of immaturity wherein, in my case, anyway, I turn back into the small child who can’t “cope” and runs for cover. When I’m ‘on the beam’, all problems become opportunities for accomplishment and excitement, rather than ‘drags’ and worry-causing disasters.

Here’s a case in point: At the end of my senior year in college, I had procrastinated myself into a real ‘jackpot’. I hadn’t started on my thesis, and was way behind in several papers for various courses. I remember taking off with the freshmen in my fraternity to go sailing when we should all have been back working on end-of semester assignments.

I had the presence of mind to go to the head of the Medical Department at my college (a renowned psychiatrist) and asked him what I should do. He simply gave me this fine advice: “Get eight hours of sleep every night and just work your tail off and get the work done!” I went back to my apartment and did just what he said. The work got finished, not up to my usual standards, but adequate enough to pass my courses and get my degree along with the rest of the class.

Another constantly repeating pattern is this: When I work toward an anticipated goal, (like planning and bringing off my mother’s funeral), I work efficiently and get a charge out of the accomplishment. When it’s all over, I get a real letdown; crawl back into the cocoon and ‘vegitate’, so to speak. What I think I’m going to have to do is anticipate this pattern and plan for something ‘fun’ after completion of the task, project, or event. This way, I can always have something to look forward to; something that I’ve earned, through my own efforts. I’m really quite a capable person, but highly self-critical and just someone who tends to program himself for failure rather than success. Then I punish myself for my subconscious 'desire to fail'.

Finally, here's my view on psycho-pharmaceuticals. They just don't work for me. Why? I'm sure all the research on brain chemistry and its effect on emotional behavior is correct. However, in my case, I feel that the endorphin uptake phenomenon and other "chemical imbalances" are the result of conscious as well as subconscious behavior, rather than the cause of it. I think I talk myself into and out of mental/emotional abnormality. When I am in a "low", I seem to prefer to stay there rather than taking steps to pull out of it. Again, sick behavior. How else can we explain the dramatic swings from high to low emotional state and the inability to cope with even the simplest challenges?

My most recent "low" was brought on by a period of relatively severe physical illness. My present 'hypomanic' state started on my wife's birthday, so it's too early to tell if my program of self-help described above is going to work as a permanent 'cure'. I certainly hope so, as I have a lot of things I want to accomplish in this life, assuming I have a few more years left.

I am presently on 1000 to 1250 mg of Depakote, which seems to be helping me avoid mania and sleep better. I use alcohol sparingly, knowing that Depakote increases the effect of any alcoholic intake. I'm comfortable with this situation and continue to improve physically.

I skipped the genetic aspect of the bipolarism. It covers my two maternal grandmother's brothers and their kids as well as my own four children who have had varying symptoms similar to my own.

Overview

Bipolar Disorder is both a psychiatric and a neurological disorder that affects about 1.2-1.6% of the population. Both sexes are equally affected. Its symptoms have been most frequently described in consumers between the ages of twenty and forty. However, recent work is showing that Bipolar Disorder is often seen in children, adolescents, and seniors as well.

The key symptom of Bipolar Disorder is periodic disturbance of mood. The consumer experiences depressions like those experienced by persons diagnosed with serious depression, and also experiences periods of abnormally euphoric, expansive, or irritable mood. The consumer's mood swings back and forth between these two moods, or poles, (hence the name). Sometimes an incident in the consumer's life may seem to trigger a mood swing; at other times a mood swing may occur for no identifiable reason. Mood swings are not the fault of the consumer; they are a symptom of the disorder, caused by a neurochemical problem within the brain.

Diagnosis

The diagnosis of bipolar disorder is usually made after a psychiatrist interviews the consumer, observes their behavior, and relates the preceding information to what is known about the consumer's life history and recent behavior. The diagnosis cannot be made without knowledge of the life history. The consumer's mood must meet, or have met in the past, the requirements for a major depressive episode, or "unipolar" depression (see previous chapter). Additionally, the consumer's mood must meet, or have met in the past, the requirements for mania or hypomania. The manic/hypomanic symptoms must last for at least a week, and include various combinations of:

- Inflated self-esteem
- Decreased need for sleep (e.g., only 3-4 hours per night)
- Increased level of activity
- Increased talkativeness (e.g., others cannot "get a word in edgewise")
- Racing thoughts
- Increased distractibility
- Increased, sometimes impulsive activity
- Increased sex drive
- Poor insight and judgement, which can lead to reckless behavior

A hypomania is not as severe as a mania, and does not disrupt the consumer's life as much. Bipolar Disorders are classified as "Type I" (depressions and full manias), or "Type II" (depressions and hypomanias). One may go from being a Type II to a Type I, but not the other way around. Anyone who has ever had a full mania has a Type 1 disorder.

Often, the consumer does not recognize hypomanic behavior as a problem and will initially see the psychiatrist for help with depression only. Sometimes, the consumer may experience symptoms of both depression and mania at the same time. These episodes are extraordinarily unpleasant for the consumer, and frequently for those close to him or her. There is a driven quality, or sense of urgency associated with these "mixed" episodes.

When bipolar disorder was first identified, at the beginning of the 20th century and before psychiatric medications were discovered, the mood swings from mania to depression were described as being months in duration. Since then, it has been observed that bipolar mood swings may be "rapid cycling", i.e., much shorter, with mood shifts lasting only a matter of days to weeks, and possibly even shorter. These kinds of bipolar disorder can be very difficult to endure, to diagnose, and to treat.

Prognosis

Bipolar I disorder is a severely disabling illness with extremely high societal costs. In a given year, it affects minimum of one million American adults aged 18 and older. Approximately 15% of consumers with bipolar disorder will commit suicide. It has been estimated that the total annual U.S. cost of the illness was $45 billion in 1990 dollars, more than the $40 billion spent that year on depression and, among mental illnesses, exceeded only by the $64 billion spent on schizophrenia. Without adequate treatment, a person with bipolar disorder beginning at age of 25 can expect to lose 14 years of effective functioning at work, school, or with family, and to sacrifice nine years of life. More recent data suggest that this translates into a *worldwide* loss of 1.7 million years of healthy life due to disability and/or premature death. This makes it the sixth most common cause of disability worldwide, second among mental illness only to unipolar depression.

In general, manias and hypomanias respond better to treatment than bipolar depressions, and many bipolar consumers, especially rapid-cycling Bipolar-II adult consumers, spend most of their time depressed. These consumers are sometimes mistakenly diagnosed as having unipolar depression, but they usually do not respond well to the usual effective treatments for unipolar depression. Males, persons with other psychiatric disorders (e.g., alcohol dependence, chronic depression between manias, psychosis), and those with histories of poor occupational functioning have worse prognoses than females, those with short nonpsychotic manias, and those with no additional psychiatric problems.

Treatment

Standard antidepressants such as fluoxetine (Prozac) and paroxetine (Paxil), though effective for unipolar depression, are usually not helpful in the treatment of bipolar disorder unless they are used with at least one other medication, a "mood stabilizer". Standard antidepressants, if used alone, can actually cause mood shifts from depression to mania. About half of bipolar consumers are adequately treated with one mood stabilizer, lithium. It is a natural element that is a mood stabilizer. For those who do not get adequate relief with lithium, other mood stabilizers are used, in addition to or instead of lithium. Many of these mood stabilizers were originally manufactured as anticonvulsants intended for use in the treatment of epilepsy. They include divalproex (Depakote), carbamazepine (Tegretol), and oxcarbazepine (Trileptal). Other medications such as olanzapine (Zyprexa), and risperidone (Risperdal), originally made to treat psychotic symptoms like hallucinations and delusions, also have shown mood stabilizing properties. Like lithium, these medicines are effective in the treatment of hypomania and mania, and to an extent in bipolar depression. A new antipsychotic, ziprasidone (Geodon), has not yet been thoroughly evaluated for use in bipolar disorder. A new anticonvulsant mood stabilizer, lamotrigine (Lamictal), appears to be more effective in the treatment of bipolar depression than in mania or hypomania.

Recently, it has become evident that bipolar disorder must be treated “from below” to deal with depression, as well as “from above”, to deal with mania and hypomania. Unfortunately, at this time there is no single medication that addresses both needs adequately, so treatment with combinations of medicines is the current standard of care. However, treatment with several drugs increases the likelihood of side effects. This is especially true if the medications interact with each other, which is the case for several frequently used combinations. Thus, coming up with the right combination of medications to treat bipolar disorder requires a close working relationship between the consumer, the psychiatrist, and other members of the treatment team.

Another effective treatment for bipolar disorder is electroconvulsive therapy (ECT). For this treatment, the consumer receives general anesthesia and a muscle relaxant. After the consumer is asleep and relaxed, a mild electric current is passed through the brain, and the brain has a seizure. The consumer, who is asleep throughout the entire procedure, shows little or no physical movement. After a few minutes, the consumer wakes up, as if from natural sleep. Several treatment sessions are necessary for the treatment to be effective. ECT is the most effective treatment for bipolar (and unipolar) depression, even more effective than antidepressants. It is also an effective treatment for mania and hypomania. The procedure is a safe one, although temporary memory interference is seen sometimes.

Although medication is seen as the mainstay of bipolar treatment, psychotherapy is also useful in some cases. Two psychotherapeutic techniques, called Cognitive-Behavioral Psychotherapy and Interpersonal Psychotherapy, have been shown effective in this regard. Each uses a different way of teaching the consumer to cope with the disorder and to minimize its discomfort. It is likely that the best treatment may include both medication management and psychotherapeutic approaches, each supplementing the other.

Consumers with bipolar disorder range from high functioning professionals to severely impaired individuals on disability. A consumer may have little or no functional impairment at times. However, at other times thinking and emotions may become extremely disordered, sometimes to the point that he or she must be cared for by others. Emotion-driven, impulsive behavior undertaken while manic can disrupt or destroy relationships, job performance, financial stability, and even physical health. Insight and coping ability may vary spontaneously, in ways that are not always obvious. It is necessary to consider the variability in insight and functioning shown by each individual consumer when constructing a treatment plan for bipolar disorder.

The American Psychiatric Association (A.P.A.) has published Practice Guidelines for the Treatment of Bipolar Disorder; these guidelines summarize a national standard of care, including suggested medication classes, medication combinations, the use of ECT, and suggest sequences in which they might be tried. The guidelines indicate that “The medications with the best empirical evidence to support their use in maintenance treatment include lithium and valproate; possible alternatives include lamotrigine or carbamazepine or oxcarbazepine.” If one of these medications is used to achieve remission from the most recent depressive or manic episode, it is recommended that it be continued. Maintenance sessions of electroconvulsive therapy (ECT) may also be considered for consumers whose acute episode responded to it acutely.

For consumers treated with an antipsychotic medication during the preceding acute episode, the need for ongoing antipsychotic treatment should be reassessed upon entering maintenance treatment; antipsychotics should be discontinued unless they are required for control of persistent psychosis or a safeguard against recurrent illness. While maintenance therapy with atypical antipsychotics may be considered, there is as yet no definitive evidence that their effectiveness in maintenance treatment is comparable to that of agents such as lithium or valproate.

Consumers who continue to experience symptoms or mood episodes may require the addition of another maintenance medication, an atypical antipsychotic, or an antidepressant. There are currently insufficient data to support one combination over another. Maintenance sessions of ECT may also be considered for consumers whose acute episode responded to ECT.

During maintenance treatment, consumers with bipolar disorder are likely to benefit from psychotherapy, which address illness management (i.e., adherence, lifestyle changes, and early detection of symptoms) and interpersonal difficulties. Group psychotherapy may also help consumers address such issues as adherence to a treatment plan, adaptation to a chronic illness, regulation of self-esteem, and management of marital and other psychosocial issues. An example of an excellent group treatment program is The Life Goals Program, developed by Mark Bauer, MD. and Linda McBride in Providence, Rhode Island. In their program, they assist consumers with bipolar disorder to think about their illness, to participate more effectively in the management of their own illness and to interact with the systems of care in which they are treated. Support groups, such as those locally offered by NAMI* and DBSA* provide useful information about bipolar disorder and its treatment. (*described in appendix)

Lastly, a new research effort, funded by the National Institute of Mental Health and called the Systematic Treatment Enhancement Program for Bipolar Disorder (STEP-BD), is evaluating the effectiveness of the A.P.A. Practice Guidelines. Results will be used to modify the A.P.A. Practice Guidelines, as new research data become available.

3

SCHIZOPHRENIA

MYSELF

I was living with my mother and I had my two children. One day my mother went to church and I was cooking. I thought I had turned the stove off, and then I lay down on the couch and went to sleep. When my mother came home from church she noticed that the gas was still on, on the stove, and asked me what was going on. I told her that I thought that I had turned it off. I think I was confused at the time.

Let me back up for a minute, before that I was taking my medicine and living with my boyfriend I had the children and I had a job. When I stopped taking my medicine I started getting really confused. I took a trip down to Columbus. I just walked out, got on a bus and went to Columbus, and stayed at a shelter down there. I tried to cash a large check I had on my person but I didn't have the identification to cash it so they um, they called my mother and that's when I went to live with my mother. That was a low point in my life because I wasn't taking my medicine and I just would go all over the country. I'd go to Texas, I'd go to Washington D.C., I'd spend time in shelters. I left town all those times because I was actually hearing voices, I thought it was God talking to me and telling me to leave town. But my dad said that that's not actually God talking to me. So then I was hospitalized. At that time I was hospitalized for 6 months, and I never wanted to really tell the doctor that I was still hearing voices because I was worried they would send me to the state hospital. I also thought that I was married to some guy; that he was my husband. I would write him letters, and the staff finally told me to stop writing the letters. I finally started to reason that I couldn't be married. But, the voices, I'm still hearing voices most of the time. So I was hospitalized for 6 months, and after that I told the doctor that I didn't want to live with my mother any more. She was getting mad all the time because I was sleeping a lot. So I looked into a group home situation. By me not telling the doctor about my problems, feelings, and the fact that I was still hearing voices, I really think I ran into some real problems.

I still have them. For example, I still think I have spirits in my body.

I wouldn't tell my doctor what I was experiencing because I thought to myself, "If I do that they would lock me up for good". But I always heard the voices; I heard good voices and bad voices. Some voices tell me good things, like "why don't you go shopping and buy a loaf of bread", and then other voices say bad things like" you're the devil".

So during this period I spent a lot of time in group-homes. Then I finally got my own place. I got into a housing assistance program and I was able to get my kids back; then my boyfriend came back. Then everything started going down hill. I left him. I went to a battered shelter, a shelter for battered women, and stayed there for a while. Then I got my own apartment. When I was in my own apartment I really didn't want custody of my kids because I thought I would hurt them, but I had the two kids and was pregnant with a third. I took off for Chicago. I didn't want to take the medicine because I was afraid it would hurt the baby. I was actually on my way to Colorado. At the bus station, I began preaching, and then somebody picked me up and took me to a mental hospital. That's when I lost custody of the kids. My mother and brother came out to Chicago to pick me up and brought me home.

I was in several hospitals, and what finally really helped me was that I got off alcohol and drugs. I was in a group home at the time and I was in and out of the hospital, but because I kept drinking, I ended up just going back to the hospital. Finally they kicked me out of the group home. Then I just started hanging around in a psychotic episode, and I was homeless and drinking liquor. I was borrowing money from a social worker that worked near the hotel where I was living. She told me that she wouldn't loan me any more money unless I went to see a doctor. She gave me the address of a mental health agency that I could go to since I was homeless. Finally, I got a case manager and got back on my medicine. I started seeing a doctor, and I really got off the alcohol because my case manager told me to stop, I don't know why I finally listened to her, but I did and it was the best thing I could have done. I also went to AA. My mind began to get out of the fog and I realized that the medicine was actually starting to work. So I first became ill around age 16-17, and by the time I was able to get it together and come out of the fog, I was 33. That's roughly about 17 years that I had a really rough time. It was really hard.

If I could give advise to parents, I think this is what I'd tell them. The parents have to get out of the way. And by that I mean, I think they are overprotective. Instead of treating the consumer like an adult, a lot of parents resort to treating them like they're just children. This can sometimes be good, but then other times it can be really bad, especially if you have a real independent thinker. Sometimes the parents can look at you and say, “Why are you doing that?” And I don’t know why I’m doing it, and this can be really bad. That’s why I say: “parents get out of the way”. I tell my friends to either go to a group home if they get the chance, or to go to some type of independent living situation. That way you avoid conflict. The conflict is between what you have in your mind and what your parents think. Whether what you have in your mind is realistic or not, those are your thoughts. It’s really hard to deal with a family member who doesn’t understand mental illness. I think at some point, they are in denial.

While you try to stay out of their way, still try to stay some part of their life. Try to be active like going to visit, inviting them to different places with you (eating out, plays). Still include them in the family activities. Encourage them to do something positive with their life.

My father used to give me motivational tapes that he liked to listen to. He wanted me to listen to them everyday, and he really thought that those tapes were going to heal me. I didn’t like that. I thought that the tapes could give me a little insight or some comfort because they included nice music. But I really didn’t think that they could heal me. I didn’t like that. And then my mother, she didn’t even want to acknowledge the fact that I was sick. When I told her that I had a therapy appointment, she would always question why I needed one. She was in denial.

Over the years I’ve been to two types of groups, one run by professionals, and one run by consumers, and the one I liked most was the one run by professionals. I’m going to a group now, and it really helps me because I get paranoid sometimes. I still hear voices. I hear the good and bad voices, but most of the time now, I hear more good than bad. What I mean by good voices, are voices that tell me to pray or tell me to leave my house when I’m afraid. I still talk to my voices. My doctor has a problem with that. I don’t know whether the voices are inside me or not, and I’m just actually talking to myself, but I find more comfort in thinking that the voices are outside of me because they keep me company. Sometimes I actually like them. Not the bad voices; I just like the good voices.

I have a brother and a sister. Sometimes my brother comes to visit me and he also loans me money. My sister is more far away, but she’s like that with everybody. My mother and father, they visit me but my sister, she doesn’t visit me. Every once in a while she’ll call me. My son is also mentally ill. He recognized his symptoms a lot earlier than I did and he’s doing pretty well. He takes his medicine. I think by watching me he decided that he didn’t want to be like me. My son saw me do some really sick things. I think I just backed myself into a corner, but I did it to myself. I just wouldn't talk to anybody about what was going on with me because I was afraid they were going to lock me up in a hospital. I worry about my second son. He's in school and trying to do well, and I'm worried that if he's under too much pressure that he also is going to become mentally ill. I watch him… he's okay, but I still worry about him. I know people who went to college and then had a nervous breakdown. If something would happen in college, that would be a real tragedy.

I was going to church one day and a friend of mine picked me up. When my friend found out that I had a social worker coming to visit, she started questioning me about whether the social worker helped me plan meals, and wrote out what meals I should have for the week. I'm a good cook! I felt angry that she (my friend) would assume that just because I had a mental illness I wasn't able to do anything. Sometimes my social worker acts like that too. They need to remember that I had two kids by age eighteen and I had a lot of responsibility. I would appreciate if people could remember that I like to cook. I make bread. I also write poetry and I would like to share one of my poems with you.

The meaning of normal

Some people say
That my thinking is
Not normal
What is
Normal, really?
Normal thinking
Would not have
Brought us
Airplanes or
TV's
What does fitting the "norm"
Actually mean?
We would have no Vision
No
Malcolm X's or
Martin Luther Kings
With
No electricity
Or normal for us
To be treated
Less than a human being?
Imagine us sitting
All in the dark
Struggling to be
"normal"

Overview

Schizophrenia is a major mental disorder that affects approximately 1% to 3% of the population. The ages of developing the illness can range from late teens to early twenties for men and mid-to-late twenties for women. There have been cases of adolescent and childhood schizophrenia; however these are very rare and appear in approximately .01% of the population. Very early in the illness, family members (especially parents) may begin to notice that the consumer starts to withdraw from social situations, shows a loss of interest in things that used to be important to them, are careless about their grooming and hygiene, and share unusual beliefs or thoughts.

Diagnosis

The *Diagnostic and Statistical Manuel of Mental Disorders* (DSM-IV) defines schizophrenia as a "disturbance that lasts for at least 6 months and at least 1 month of two or more of active-phase symptoms." Active phase symptoms include delusions, hallucinations, disorganized speech, or grossly disorganized behavior. Delusions are false beliefs or distortions of thinking. An example of a delusion is when a person believes that the CIA is after them, or that he/she is a religious prophet. Hallucinations are hearing, seeing, smelling or feeling perceptions or sensations. Hearing is the most common type of hallucination. Disorganized speech demonstrates a thought disorder and is presented by incoherent speech and loose connections between thoughts. Disorganized behavior ranges from age-inappropriate behaviors to unmanageable hygiene to repetitive behavior.

One way of classifying the many symptoms of schizophrenia is "positive" or "negative". The **positive symptoms** include *hallucinations, delusions, disorganized speech and disorganized behavior.* The **negative symptoms** of schizophrenia include a decrease in interest in pleasurable activities, decreased motivation, and diminished facial expression. These symptoms are called negative, because they should not exist in a healthy person.

Five different types of schizophrenia and their definitions are presented in the next Table:

1. **Paranoid Type**: organized auditory hallucinations and delusions, which may indicate that someone is after their life or that they are in harms way. Disorganized speech is not prominent in this subtype. This subtype is the most common.
2. **Disorganized Type**: disorganized speech and behavior, and inappropriate facial expressions. May demonstrate inappropriate hygiene routines, silliness, and laughter.
3. **Catatonic Type**: major feature is disturbances that may increase or decrease mobility, parrot-like speech, and involuntary imitation of movements of others.
4. **Undifferentiated Type**: presence of symptoms of schizophrenia are present, however do not fit in a specific subtype.
5. **Residual Type**: this category is used when prominent symptoms are absent or have resided for some time. However, negative symptoms may be present along with very mild positive symptoms. This subtype is used in between a full-blown episode and complete remission.

Prognosis

In some consumers, prognosis can be favorable if schizophrenia is diagnosed and treated soon after it is diagnosed. However, some physicians and other mental health professionals may have difficulty in diagnosing schizophrenia since some of the negative symptoms (i.e. social withdrawal and decreased interest in pleasurable activities) are shared with some mood disorders diagnoses such as depression. Generally, prognosis is very much dependent on the type of treatment and staying on a prescribed medication regimen.

Treatment

The treatment of schizophrenia is multi-faceted**.** The most important facet is medication that helps to control symptoms and to help correct a chemical imbalance in the brain cells. The medications used to treat schizophrenia are called “anti-psychotics” or “neuroleptics” and have been approved by the Food and Drug Administration (FDA) to treat psychotic symptoms and disorders. These medications are listed in two categories: *typical* and *a-typical*. The past decade has formulated the newer medications, called the *a-typicals*. **It is recommended that medications be used for at least a 6-week trial with adequate dosing before switching to a different medication.** Some psychiatrists may use a variety of medications before obtaining symptom-relief and improvement in their consumers. The Table below provides the chemical and trade names respectively.

ATYPICAL	**TYPICAL**
clozapine (Clozaril)	fluphenazine (Prolixin)
risperidone (Risperdal)	chlorpromazine (Thorazine)
olanzapine (Zyprexa)	haloperidol (Haldol)
quietiapien fumerate (Seroquel)	thiothixene (Navane)
ziprasidone (Geodon)	trifluoperazine (Stelazine)
	perphenazine (Trilafon)
	thioridazine (Mellaril)

As with any medication profile, side effects do exist. Side effects that are most common are: dry mouth, constipation, blurred vision, and drowsiness. Less common side effects: decreased sexual desire, menstrual changes, stiff muscles on one side of the neck and jaw. More serious side effects include restlessness, muscle stiffness, slurred speech, and tremors of the hands and feet. Approximately 1% of persons on clozapine develop agranulocytosis; this is a very serious blood disorder that involves suppression (or lowering) of their production of white blood cells. To monitor and prevent this side effect, persons on clozapine get their blood checked weekly or bi-weekly. Lastly, tardive dyskinesia is an involuntary facial movement and sometimes twisting or jerking of other parts of the body. This condition usually develops in older consumers; 15-20% of them have been taking antipsychotic medications for many years. Other types of medications (i.e. Cogentin) help with muscle rigidity. Medications are available to help alleviate the discomforts of side effects. We encourage that family members contact the psychiatrist or pharmacist for more details.

In most treatment, a treatment team helps the individual as well as the family cope with schizophrenia. In many community centers, the treatment team usually consists of a psychiatrist, case manager, and sometimes a nurse. The *psychiatrist*, can be a M.D. (Medical Doctor) or D.O. (Doctor of Osteopathy). In order to become a psychiatrist, a doctor must specialize in the field of psychiatry during their four years of residency. The psychiatrist is responsible for medication management to monitor a proper medication regimen. The *case manager* is someone who works in the social services arena and has received their Bachelors of Science or Art degree in psychology, counseling, social work, human services or other related field. The case manager is usually experienced in managing individuals with mental illness under the supervision of a supervisor who has received their Master’s degree and licensure. Goals of community treatment are to help the consumer become as self-sufficient as possible. The case manager helps the consumer manage finances (i.e. set up a weekly allowance), participate in activities to enhance social skills, use public transportation, get to appointments, and buy groceries. The treatment team meets with family members to discuss consumer progress. The *nurse* is a Registered Nurse who monitors the medical needs that do not need a psychiatrist. Some nurses make home visits to monitor medical needs such as monitoring blood count due to diabetes or due to the type of medications.

Group therapy is a widely used therapeutic treatment for schizophrenia. Two examples of this treatment include a life skills group and a family education group. A life skills group focuses on helping the consumer with schizophrenia learn or relearn day-to-day skills that range from personal hygiene to money management. Family education groups focus on information about the illness, practical advice to handle the positive and negative symptoms of the disorder, and supportive service that are available in the community.

Lastly, participating in clinical research is yet another treatment option. Grants funded by the National Institute of Mental Health and private pharmaceutical companies support research efforts related to the discovery of new and improved medications for schizophrenia. Family members are encouraged to contact their nearest academic medical center or community mental health center for more information on clinical research opportunities.

4

SUICIDE

The death of a loved one by suicide is, for most of us, an incomprehensible idea. But the fact is that nearly 12 of every 100,000 deaths in the United States each year are by suicide. That makes suicide the 8th leading cause of death in our country.

The following is an actual suicide note written by an adult consumer, which eloquently speaks to the heart of the matter. That is, "why would any one think this way?" In reading it one can see the hopelessness, the anger, the frustration experienced by the suicidal individual. Note also the predominant mood and the hints of ambivalence that are quickly dismissed.

> Before I went into the hospital 90% of me had completely given up on life. I never completely regained hope once I began to feel better. Since I've been out of the hospital things have not gone well. A percentage of myself is once again beginning not to care. Or is it that caring is too difficult? It is so easy for me to give up and attempt to kill myself. I am tired of the struggle. I don't see life as most others do. I see it as a fight to stay alive and deal with this depression. I can't seem to shake the past, deal with the present or find hope in the future. I do not know how long I will be able to continue. I believe that my death will be a direct result of a suicide attempt. That is how strongly I feel about getting out of this life. I could go into the hospital twice a month and nothing will ever change. The past hospitalizations were a waste of time because in the end I will succeed in what everyone has attempted to keep me from doing the inevitable has been delayed once again. I wish I didn't think this way, but unfortunately I do. I am not trying to be difficult. I just don't want to continue with this existence. I wish someone would bring me that little pill that would guarantee that I'll never wake up again. Unfortunately it will never happen. I have to continue trying on my own and deal with the consequences if I chicken out or fail. If I could erase the memories and relive my past maybe I could deal with life. Maybe I would want to live like normal people. Why do I have to go through these mood swings

> day after day? I can't seem to make anyone else understand that it's not worth it. Not if I have to deal with feeling like this.
>
> You never really know what it is like unless you've been there. Suicide is not an option? Well it is for me. If you can't put yourself in my place because you've never been there you don't have the right to tell me I can't off myself. The Hell with you! Suicide is the only thing I have to hold onto! It is my hope! It's my reassurance that I will always have a way out of this Hell that normal people call life!
>
> I don't want to get up in the morning and go through the motions of life. I wish I could just sleep through the rest of it or at least have the guts to end it once and for all. Each day that goes by I become more and more tired of it. One day I will succeed. I refuse to live out the remainder of this life. I refuse to.

This note gives an indelible impression of what one feels like when a person is intensely suicidal. The warning signs voiced in this note are common to many cases of suicide. First there is depression, hopelessness, anger and volatility. This person refers to multiple previous suicide attempts. There is a sense of extreme isolation and a lack of support in their life; a lack of connectedness, meaning or hope. In fact, hope has been turned upside down in an irrational, nearly psychotic manner. Hope for her rests with death not life; an opportunity to escape the insufferable pain that she is feeling. There is a hint of bipolar illness that is an ominous sign because 15-20% of individuals with bipolar illness will die by suicide if left untreated. We do not know this person's age though studies have shown that the older one becomes the more risk they have of completing suicide.

We also do not know for certain what kind of social supports the author of this note has - though we could almost assume that they are weak. No mention of a spouse or significant other is made. The plan of suicide by poisoning is voiced more than once. There is no mention of a life of substance abuse or alcohol problems. Neither is there mention of chronic illness other than chronic mental illness.

One way that clinicians use to assess the risk of suicide involves the help of the acronym “SAD PERSONS” which was developed by Patterson and colleagues (1983). This details of this acronym are presented in the Table.

- **Sex**: women attempt suicide more often than men, but men actually kill themselves more than women.
- **Age**: Teens and the elderly have higher risk for suicide.
- **Depression**: Suicide rates are higher in depressives than the general population.
- **Previous attempts**: 25%-50% of persons who kill themselves have previously attempted to do so.
- **Ethanol** (or alcohol) abuse: There is an increased risk of suicide in alcoholics.
- **Rational** thinking loss: Any psychosis presents a risk if judgement is impaired.
- **Social supports** lacking: The suicidal person often lacks relatives, friends, employment and religious supports.
- **Organized plan**: The person with a well defined, specific plan with a lethal available method is at very high risk.
- **No spouse**: Divorced, widowed, separated or single persons are at higher risk than married persons.
- **Sickness**: Chronic, debilitating and severe illness is a risk factor for suicide.

Generally, if a person has 0-2 of these indicators, their risk of suicide is low. If a person has 3-4 of these indicators, their risk is moderate and warrants intervention by a mental health specialist. If a person has 5-6 risk factors, they should be treated in a day treatment program. If a person has more than six risk factors, they should be hospitalized.

While this acronym is helpful, there are other factors to consider. These include the presence of severe anxiety, a complete loss of interest and pleasure in doing usually pleasurable activities, a history of violence or impulsivity, severe insomnia, recent discharge from a psychiatric hospital or the recent diagnosis of any serious physical or mental illness. It is hard to prioritize which of these factors carry the most significance and so family members and clinicians must use their individual judgment. But, making a person "promise" not to kill themselves is not likely to be of any benefit or more than false comfort to the person coercing this promise out of the suffering consumer. One must accept the realities of the situation and characterize the intensity and extent of the person's suicidal thoughts.

Ask yourself these three questions:

- What methods or plans have been fantasized or made? Ask the person directly if they made any practice attempts or failed attempts and how recently.
- What degree of intent to commit suicide rests with the individual? Ask the person directly about the seriousness of their plan. Do they really intend to die?
- What prevents them from acting out their ideas? Determine if there is any obstacle to carry out their plan. For example, if the plan involves a weapon, is the weapon available?

If a person has persistent suicidal thoughts, plans and intent then they require hospitalization. Once hospitalized, there are a number of interventions, which can be extremely effective in reversing the depression, anxiety and hopelessness. Medication treatments, psychotherapy and social interventions can stem the tide of a suicidal illness. Suicide is, in the vast majority of consumers, a sign of serious mental illness brought on by real or imagined stressors. What you must understand about suicide is that it is a warning sign to heed and measure. Having done so, you can then aide the sufferer in regaining hope, relieve suffering and to recover their lives.

What happened to the consumer who wrote this note at the beginning of chapter? She was hospitalized at least two more times. Finally, a medication regimen seemed to help her along with regular psychotherapy.

She went on to have a baby, which added tremendously to the meaning she held for life. Though she continued to struggle with depression, her new goal became determination to give her daughter a better life than her own.

TEEN SUICIDE

Suicide is the third leading cause of death in young people aged 15-24. Suicide in teenagers is difficult to predict or prevent because many risk factors are not recognized in advance. Also many teenagers who commit suicide come from supportive families. Zametkin and colleagues (2001) cite the following "alarming" risk factors.

Previous suicide attempt
Recent personality change
Psychosocial stressor (trouble with family or friends; disciplinary crisis)
Writing, thinking or talking about death or dying
Age 16 years or older, male, and living alone
Altered mental status (agitation, hearing voices, delusions,
violence, intoxication)
History of physical or sexual abuse

Family members of teenagers with serious mental problems should work together with physicians in clinical practice to determine the best level of supervision and treatment for a suicidal teen. Know the symptoms of depression and the risk factors for suicide. Always keep firearms and other lethal means locked up in the home and watch the teen for signs of substance abuse and poor school performance. Pay particular attention to teens who were recently hospitalized or those with multiple suicide attempts.

If any teen has persistent suicidal thoughts, plans and intent then they require hospitalization. Heed any warnings. Once hospitalized, there are a number of interventions that can be tried which treat the depression, anxiety and hopelessness. These include medications, psychotherapeutic and social interventions. Suicidal thoughts and behaviors are probably signs of serious mental illness brought on by real or imagined stressors.

5

ALCOHOL AND DRUG ABUSE

My Sister

I grew up as the oldest child in a large, prosperous family, with my sister. Carolyn followed me closely in age and we developed a special bond as the two “little mothers” of the family. Our mother trained us early in every aspect of childcare and housekeeping. After our youngest sister was born with multiple handicaps, our mother slipped into a deep depression that lasted four or five years, coinciding with my teenage years. It was left to Carolyn and me to make dinner and watch over the younger children.

Being number two, Carolyn was very competitive and worked hard to prove that she could do everything as well as I could. She loved the babies more, she cleaned the house better, she practiced the piano more, and she studied harder in school. Carolyn’s competitive nature seemed extreme to all of my siblings, but we admired her for it.

By the time Carolyn and I entered college, we were both angry with Mom. We cemented our bond with alcoholic venting sessions about our lost teenage years. When I visited at her college, I noticed that she increasingly used more and harder drugs. She told me that she was doing LSD every day, and I worried about her. But because I too was involved in binge-drinking and occasional marijuana use, I didn’t think I could say anything to her. I just assumed she was cooler than I was, and I knew how determined she was to be a success so I didn’t think she would let the drug use go too far.

We both made it through our college years, but not without some angst. I lost a friend to suicide, and that summer Carolyn told me that several of her friends had died. After graduate school, Carolyn found the job that any graduate student dreams of, with fulfilling work and a promising future. I visited often, and listened to her stories about her job problems, her “crazy boss”, and a harassing neighbor. None of these stories seemed unusual to me. I thought it was just the city life of a young professional. I too had a budding career, and my own problems.

After a couple of years in the working world, I came to see that I could not control my drinking and found the help to stop.

Carolyn supported herself, but she became increasingly alienated from people. A high school friend would say the wrong thing. A college friend would question her choices. One by one, Carolyn removed herself from the people in her life. She went to therapy, briefly, but disagreed with the therapist's approach. Somehow, she maintained contact with several of our siblings and me, but distanced herself from our parents.

One night Carolyn called me and told me that our father had abused her as a child. Although I found this difficult to believe, I trusted and believed her. Thus began a painful and confusing period for me, a time when I questioned my family, my beliefs and even my own mental health. To deal with the pain and confusion, I entered therapy with a social worker who totally bought into my sister's delusions. Events during this time were very painful, and I did not know what to do except cry. I went back to my city and my job and my adult life, and did not contact my parents for several months. During that time, Carolyn called me frequently and reported more memories of abuse.

Carolyn was cleaning houses for a living. A friend invited her on a trip oversees, and she left the country for a month. When Carolyn returned from her trip, she told me that she had recalled that all of our extended family had been involved in satanic rituals. I loved my sister and had wanted to be supportive of her. Now I thought she was delusional, and that my support had done her no good. All I had done was to make life more difficult for my father and mother. How could I have been so naïve?

A new therapist (a well-trained psychologist) helped me put my actions and feelings in perspective. Looking back, I could see evidence of Carolyn's paranoia ever since college years. The friends she had cut off, the boss who was out to get her, the neighbor who forwarded her mail to Alaska. I had no evidence that these things weren't real, but I had no way to find out. I remembered Caroline telling me after college that several friends had dies. I called another of her college friends who said that he knows that at least one of them was alive, and that he thought he would know if any of the others had died.

Eventually, I found the courage to question Carolyn's memories. I did not use the word "delusion", but she knew that was what I meant. I wanted to get help for her, but I did not know how to do it. As I expected, Carolyn treated me the way she treated any friend who disagreed with her. She cut me off. I did not hear from her for several years.

I married and had a child, and sporadically tried to keep in touch with Carolyn. She occasionally sent me a Christmas card, sometimes returning the money I sent with my card and accusing me of being complicit with the family's "satanic cult". At various times

I called her and tried to see her, but she made excuses. Other family members also approached her, and my father made a surprise visit where he tried to convince her to get psychiatric evaluation. She tried to convince a priest to perform an exorcism on him. She said that my father was the evil one, and that she was not insane.

My last contact with Carolyn occurred over a period of months when I was pregnant with my second child. Carolyn apparently decided to try to "save" me, and wrote me long letters trying to convince me to go to the police and tell them all I knew about the family cult. If I didn't, my soul would be lost forever. I answered the first few letters, glad that she had made contact but worried about what she was saying. When I didn't answer soon enough, she sent more letters berating me for not answering. After a while I received a letter every day, sometimes two. I dreaded looking in the mailbox. I worried about her, and I worried that my stress level was affecting my unborn baby. Eventually, she stopped writing and stayed out of touch with the family. I have tried to track her whereabouts using Internet databases, but I don't want to trigger her paranoia.

It has been my life's regret that I have not been able to find a way to help Carolyn. I struggle with sadness, anger, disappointment in myself, and fear that she will try to "save" me again. But I have come to see that right now I cannot do anything for but trust that she is in God's hands. After several years of no contact at all, she recently contacted one of my sisters and said that despite rumors to the contrary, she is neither evil nor insane. And she is proud of the fact that she has never been medicated.

I hope that her undiagnosed disorder is one that can be successfully treated with medication. I hope that one day that she will choose to look for help and treatment. I love and I miss the person she was. I grieve our lost friendship. I am grateful that I have a healthy life with a good family and friends. I wish Carolyn has the same, but I know she is on her own path and she will have to find her own way.

Overview

It's been estimated that about 20% of the general population meet criteria for having abused alcohol or drugs during their lifetime. Among the top ten causes of disability worldwide, five behavioral and mental health illnesses make the list. They include major depression, alcohol abuse, bipolar disorder, schizophrenia, and obsessive compulsive disorder. Alcohol abuse ranks number four in its prevalence and impact. Although not completely conclusive, the best evidence suggests that about 15% of those who abuse alcohol or drugs have a co-occurring serious mental illness such as bipolar disorder or schizophrenia. On the other hand, the prevalence of alcohol and drug abuse increases to 25 to 35% in consumers with Major Depression and Schizophrenia compared to the general population, and further increases to 50 to 60% in Bipolar Disorder. The data suggest that Bipolar Disorder is the most likely serious mental illness to occur with a substance use disorder.

Diagnosis

In the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition* terminology, the words used to describe consumption of substances include "abuse" and "dependence." Abuse usually involves a maladjusted, repeated pattern of consumption that has resulted in major negative effects on family, work, or school. On the other hand, dependence implies the development of more serious and advancing problems that include physical, psychological, behavioral, and social consequences. The physical symptoms include tolerance (i.e. getting less effect from the same amount) or withdrawal symptoms. Additionally, a substance-dependent person usually has difficulty controlling the use of the substance or cutting it down, despite knowledge of having problems likely to be caused or worsened by its use. It's important to note that dependence can occur with or without physical symptoms. Compared to those who present with 'abuse', consumers who present with dependence frequently need more aggressive and comprehensive treatment.

Diagnosing a mood disorder in the presence of an alcohol or drug abuse disorder can be very difficult because the use of drugs or alcohol could trigger a wide array of effects and symptoms that imitate almost every psychiatric disorder. Consumers with an alcohol or drug abuse disorder can frequently present with generally nonspecific symptoms such as anxiety, symptoms of depression, or problems with sleep, motivation, and concentration. The use of hallucinogens, for example, can mimic the symptoms of schizophrenia; and the use of stimulants such as amphetamine or cocaine can mimic the symptoms of Bipolar Disorder. In particular, stimulants can cause mood elevation, which can be hard to distinguish from the elation experienced during the manic phase of Bipolar Disorder. In addition, many who abuse stimulants report increased energy, decreased appetite, grandiosity, and less commonly, paranoia. All these symptoms could occur independently in a typical manic episode in the course of Bipolar Disorder. On the other-hand, the frequent and persistent use of alcohol and other sedatives such as sleeping pills is often associated with depressed mood, difficulty with concentration, the inability to enjoy activities that are normally pleasant, and problems with sleep.

A physician or clinician can distinguish the symptoms of serious mental illness from those of an alcohol or drug abuse disorder by obtaining a detailed history in the presence of a family member or significant other regarding the pattern of presentation over time. Most often, drugs that get abused tend to lead to symptoms following use. Serious mental illnesses tend to cause symptoms that are either repeated or chronic, and lead to a return of symptoms for no apparent reason and frequently in no association with the drugs that someone might be abusing. When a physician or clinician is trying to determine if someone has a separate serious mental illness or an alcohol or drug use disorder, they consider the possibility that the consumer may have both. Hence the term "dual diagnosis". Having both illnesses at the same time makes the treatment more difficult. Conventional interventions are likely not to work, and generally worsen the overall impact. In addition, it has become quite clear that alcohol and drug abuse can worsen the suicidal thoughts that accompany other serious mental illnesses, and that the two together increase the prevalence of suicide attempts.

Treatment

The standard of care in the treatment of a serious mental illness accompanied by an alcohol and drug abuse disorder is to provide treatment for both illnesses at the same time, and preferably by the same team of health care professionals. Ideally, the treatment for the serious mental illness should include both medications and psychotherapy. However, the availability of treatment varies with health plans, and consumers may have a particular preference as well.

The standard of care in the treatment of an alcohol or drug abuse disorder depends on the severity of the problem. 'Abuse' frequently leads to formal treatment, but not always. 'Dependence' on a substance is always viewed as being a more serious problem, and should always lead to treatment. The primary objective for treatment is usually complete abstinence, and this almost always involves attendance at a 12-step program such as *Alcoholics Anonymous (A.A.).* This international fellowship of men and women is nonprofessional and membership is open to "anyone who wants to do something about his or her drinking problem *(see Appendix)*.

The next step is to identify triggers and circumstances that might lead to relapse (worsening) and the ones that would help maintain sobriety. The cornerstone in the treatment of any substance use disorder is to treat it as chronic repetitive disorder, as any other chronic medical problem such as hypertension or diabetes. This approach should lead the way to establishing a long-term, comprehensive treatment plan.

Incidences of relapse (or worsening of symptoms) are complicated and provide important learning experiences for you (the family member), the consumer and the treating clinician. **One of the most devastating pitfalls is that you consider substance use disorders as habits that could be dealt without seeking professional help.** Additionally, the treatment for ‘dependence’ includes intensive chemical dependence care, which involves several hours of care at least several days per week for several weeks. This is typically followed by ‘aftercare’, which involves once weekly meetings for several months. Rarely, a dependence on a substance may be severe enough to require that the substance be gradually weaned from the body to avoid potentially dangerous withdrawal symptoms. This can be conducted in the hospital setting, or more recently, in a closely monitored outpatient setting. Recently, physicians use medications to decrease the intensity of craving in substance use disorders, or to address other aspects of the disorders. Other medications are under investigation.

When alcohol or drug use disorders co-occur with other serious mental illnesses, they may look less severe than symptoms in persons who only have alcohol or drug use disorders. However, you should not think that this is less of a problem. Actually, the treatment plan for someone who has both a serious mental illness and an alcohol or drug use disorders is always complicated and more difficult. Generally, a relapse in or the undertreatment of either condition will inevitably lead to failure in the treatment of both, and will have a devastating impact on the quality of life of the suffering person.

The presence of an alcohol or drug abuse disorder is currently viewed as being a predictor of non-response to conventional treatment. In most instances, consumers need to be treated for both illnesses at the same time. Since consumers who have both disorders typically need separate treatment plans, treatment for serious mental illnesses accompanied by alcohol or drug abuse require more treatment sessions. In the current health care environment, which typically provides no more than 15 to 20 annual visits per year, this frequently results in persons being required to pay out-of-pocket during the second half of the calendar year. Consequently, that leads to an added hardship on consumers suffering from both conditions and their family, and inevitably increases the rate of noncompliance or dropping out of treatment. It has become an unquestionable observation that the management of serious mental illnesses accompanied by alcohol or drug use disorders represents a major unmet health care need and the next frontier of behavioral health research.

First-Episode of Psychosis

My Daughter

Jennifer has a diagnosis of Schizoaffective Disorder that started at age 18, when she went into the service. At that time, she wanted to get away from me, the house, and everything. She wanted to go somewhere new. Well, the service was certainly a new environment for her! During her training, her troop was only to have a certain amount of food. One night, she and a few others got hungry so they went into the kitchen to get some food. They took some bread and tried to get back into their rooms. But, someone told on them. They were singled out and made to do a lot more work than usual. They got no food, no water, no rest, nor anything else. They were made to stand for hours in the hot sun. This was their punishment. That's when it happened. She felt that she had become dehydrated and was physically affected. She was undeniably medically and mentally affected. She wound up in the hospital there on the base.

We got a telephone call telling us what happened, telling us we had to come and get her. So my husband flew down there and brought her home. Then she had to go right to the hospital. We asked, "What happened? What went wrong?" Then she just fell apart. She was very unsure of herself, paranoid, and she was questioning everything. She started to blame unrealistic things on unrealistic people. Her expectations were such that we didn't know what to do. We were walking around on eggshells. We talked to the doctor and he said, "this is what's going on, and you're going to have to deal with it". The doctor told us that she needed a therapist, a doctor, and probably medicine. So we were prepared for that, but not for what "bipolar" really meant. Even though I was bipolar; it's different when it's you. But my being bipolar helped. I could understand a little what was going on inside, but it was my daughter. I didn't really know how to help her.

Jennifer was hospitalized for two weeks. When she got out she came back home. She would just lie on the sofa shaking. She would be in tears. I would come up and sit next to her and hold her. As a mother, I hated to see her like that. It was difficult, but I just knew that there would be a light at the end of the tunnel. She would be ringing her hands, shaking, and crying out "how do you know it's going to be ok?" She would ask, "Am I ever going to be back to normal?" I would say, "yes, it's just right now that it's tough." She would be fine for about 30 minutes. Then she would want to shadow me--walk right behind me. That drove me up a wall until I realized that she needed to be with other people. This made her feel safe. That's what she needed. She felt so little of herself that I needed to build her up. Not to give her false impressions of herself, but to validate her.

Jennifer went into outpatient treatment at a hospital. It was just one meeting a day. Sometimes they wanted you (the parent) to stay and sometimes they didn't. That was only for two weeks; then she got a doctor. She has been back and forth most of the time. She's on medication. Now she's in a rehab program and she is also seeing someone in a nearby mental health center. That's really great for me because it lets us know that other people are involved. That person is licensed. It has been very helpful.

How did I feel? I felt very guilty, I felt very jealous against people who had children who were "normal"—that was hard. But all through this, I just had a feeling that there would be the light at the end of the tunnel. I would tell my daughter the same thing in hopes that it would lift her spirits. I would most definitely listen to her—that is very important. Also, don't discount what they feel. Instead validate it. I would help her back to the voice of reason, help her sort out her feelings. Cognitive therapy helps -trying to help her get away from her terrible thinking. Sometimes when you're affected you go around and around in circles and you can't get out of the negative thinking and feeling.

What advice would I give? The best advice I could give to anyone who is facing this is to find out as much as they can about the illness. They should also be involved, which doesn't mean being on the board of trustees. I went to NAMI and got a lot of good resources. Don't be afraid to be with your child, but be positive. Even if you don't think the end of the tunnel has light. Believe, and your belief will be transferred.

You should also listen to them. Try to remind them of the things they did well, or the positive memories. My daughter and I were not always close, but we were able to create that relationship.

It's been 8 years. My daughter has a job now. She is still on medication. She doesn't feel that she is as advanced as other people her age. I think she is where she is supposed to be right now. Nobody is judging her.

What is first-episode psychosis ?

Rather than focusing on a specific diagnosis (such as Depression, Bipolar Disorder, or Schizophrenia), some clinicians and researchers are interested in “first-episode psychosis”, a period of time that happens in the early phases of psychiatric illness for many young people, such as Jennifer. In their study of first-episode psychosis, Dr McGorry and colleagues (2002) include three criteria in their definition of psychosis:

- *Symptoms*- hallucinations (sensory experiences that are not real), delusions (fixed false beliefs), or disordered thinking.
- *Frequency of symptoms*-at least several times a week, and
- *Duration of mental state* – a change lasting longer than 1 week.

What is the prodrome ?

The term “prodrome” usually refers to a pre-psychotic phase that involves a change in the person’s functioning. Its most common features include sleep disturbance, anxiety, irritability, depressed mood, poor concentration, social withdrawal and some behavior problems. Nonspecific prodromal signs can worsen into psychotic symptoms. It is difficult to pinpoint the actual moment when psychosis first begins because, in most cases, the mentally ill person’s prodrome may be lengthy and range from 2 to 5 years.

Investigating the Early Stages of Psychosis

Clinicians and researchers who study the early stages of psychosis are interested primarily in early detection of psychiatric illness so that interventions (or treatments) can be started. Hopefully, early treatment can prevent the progression of the illness or positively influence the course of illness. Over a 10-year period, Dr. Jeffrey A. Lieberman and colleagues at the Hillside Hospital in Glen Oaks, New York, studied 118 consumers admitted to the inpatient services for their first-episode of psychosis. Important findings from this study are presented in the Table:

1. **Consumers had been ill for an extended period of time prior to the hospitalization. The average length of time was 71 weeks.**

2. **When assessed and treated carefully, more than two-thirds had a good recovery. Treatment included low dose atypical antipsychotic medication.**

3. **Women were more likely to respond to treatment than men.**

4. **Consumers were maintained on medication for one year. After 1 year, they were given the option of discontinuing their medication if they were clinically stable.**

5. **The risk of relapse was five times greater for those not taking medication than for those taking medication.**

These researchers concluded that many consumers in their first-episode of schizophrenia respond well to antipsychotic drug treatment in a relatively short period of time (average of 9 weeks).

Family Reactions

“Nothing can prepare families from the shock and devastation of watching a child become totally consumed and incapacitated by psychosis” April Collins, The Early Stages of Schizophrenia

April Collins, from the Continuing Care Program at the Centre for Addiction and Mental Health in Toronto, Canada, described reactions that families go through with a first episode of psychosis. These stages closely reflect the experience of the parents in our personal story.

I. Prodrome and First Crisis: At first, the family is unaware of the magnitude of the problem. Symptoms and behaviors are often attributed to other causes (such as adolescence or “a bad marriage” or a “tough job situation”). When the symptoms and behaviors persist, the family seeks help. When the behavior is labeled a “psychiatric disturbance” the family is shocked, fearful and anxious.

II. The Initial Period of Adjustment: During this phase the family has many meetings and discussions with mental health professionals to try to understand the mental illness and what it means for them and the consumer. This is a period of “excruciating vulnerability and uncertainty”. During this time family members experience intense emotions. Feeling range from anger to sadness, from wanting to control everything to feeling unable to control anything, from wanting to protect the mentally ill person to wanting to escape the overwhelming situation.

III. The Development of a Long-term Illness : During this phase the family realizes that the psychosis is indeed a ‘first-episode’ and that illness will not be cured. While the family holds out hope that a miracle will fix everything, the reality of the illness sets in. For most families this means that they have to give up things to adjust to the illness, especially hopes and dreams for the mentally ill person’s future. Caregiver responsibilities have to be sorted out and grief reactions occur.

Outpatient Treatment or Hospitalization?

According to Dr. Zipursky, it is becoming increasing common to treat individuals in their first-episode psychosis in an outpatient setting. After the physician rules out medical conditions as cause for the illness, the primary goal of assessment and treatment is to prevent the progression of the illness. Therefore, it does take some time to gather information about the illness and to make an accurate diagnosis. Because of the psychiatric stigma associated with having a mental illness, mental health professionals are particularly careful. Dr. Lieberman and colleagues indicate that a formal onset of Schizophrenia usually occurs when a psychotic episode occurs. Also, Depression or Bipolar Disorder can co-occur with psychosis. The presence of a supportive family available to provide information and close supervision often allows for the consumer to stay at home.

Inpatient hospitalization (often involuntarily) during their psychotic episode occurs because the consumer presents a danger to themselves or others. Hospitalization is often indicated for threatening behaviors or suicidal thoughts. The hospital provides safety, while the treatment team sorts out information about the history and features of the illness. Initially unclear, the physician has to determine the *"minimum effective dose*" of antipsychotic medication for each consumer. This is the lowest dose that produces the best response with the least side effects.

Readmission

Dr. T.J. Craig and colleagues (2000) examined reasons for readmission to a psychiatric inpatient service for 402 first-admission consumers diagnosed with Schizophrenia, Bipolar Disorder with psychosis and Major Depression with psychosis. During their first year after discharge, about one-third of their sample were rehospitalized one or more times. The largest percentage (43.3%) was found for consumers diagnosed with Psychotic Depression. Also, consumers with Bipolar Disorder and Psychotic Depression were more likely to be readmitted within 3 months of discharge.

Interestingly, these researchers distinguished *rapid readmission* (i.e., readmission to inpatient status within 3 months of discharge) from delayed *readmission* (3-12 months after discharge). Their findings indicated that rapid readmission was "specifically and significantly associated" with consumers having active symptoms and mood symptoms at discharge.

Rapidly readmitted consumers were also less likely to have received mood stabilizers or antipsychotic medications at discharge. In contrast, delayed readmissions were significantly associated with to nonadherence with medication regimen after discharge.

These findings support the importance of making sure that the consumer is clinically stable at discharge and prescribed the best medications for their active symptoms. Once clinically stable, monitoring and reinforcement of the medication regimen is an important function for concerned family members.

Hope for Recovery

Families play an important role in the early stages of psychosis. You are often the first persons to notice personality or behavior changes and could influence the consumer to get care for their symptoms before they worsen. Studies of first-episode psychosis that involve Schizophrenia, Bipolar Disorder or Depression highlight the importance of getting consumers into assessment and treatment in the prodromal phase or very early in the psychotic phase of their illness. For many consumers, the earlier their treatment, the better their chance of a good recovery.

Part II

CARING

7

Family Reactions

Our Son

It has been many years since I've thought about the onset of Jim's mental illness. It was in the first year of college when we really knew that something was dreadfully wrong with his thought process and behavior. It was scary and we didn't know why he quit college after one semester. He decided to travel. First, he went out west with a friend to visit one of his brothers who was also taking time off from college. Then he and two of his brothers went to Morocco. I know that they were smoking hashish then, and it worried me greatly. But, my mind was also on the three children who were still at home.

When Jim returned home that fall, it became very evident that we must hospitalize him. He told me that he could hear what I was thinking and he became very angry and stormed out of the house. When he returned and was dancing around the front yard like a Massai warrior. I called my husband at the office and frantically asked him to come home and take Jim to the psychiatric hospital. I was afraid of him and what he might do to me after the strange way he acted that morning.

That was our first experience with a psychiatric hospital and I felt strange being there, but relieved that Jim was getting some help and evaluation. I felt uncomfortable in the presence of any psychiatrist because I thought everything I said or did was being analyzed too. But that feeling went away gradually as I became more familiar with many doctors through all eight of Jim's hospitalizations!

My husband and I were convinced that marijuana was causing a lot of Jim's problems although our first psychiatrist assured us that the *schizophrenia* would have developed with or without the use of street drugs. In any case, Jim's symptoms were worse from the effects of many street drugs.

When he was finally accepting his medications on a regular basis, it was obvious that marijuana sabotaged the effect of the neuroleptic drugs designed to help the schizophrenia. We then sent him to a drug rehabilitation facility for a month, and it helped him to accept and understand what street drugs do to the brain. He has been much more compliant with only occasional slips since then.

As parents, we don't emphasize enough what significant progress has been made in the development of effective medications prescribed by psychiatrists. It takes some trial and error, but find the psychiatrist who will find the right combination of medications (often it takes more than one). It is so important that the medications be taken as prescribed. We have learned that the combination of a good psychiatrist with the right medications will work wonders. Our son is a success story.

During these past twenty-five years, one of the most helpful organizations for us has been NAMI. A nurse first mentioned it to us during one of Jim's hospitalizations. She thought we'd be interested, and off I went to St. Louis to one of NAMI's early conventions. I learned so much about the disease, the medications (used during the 80's). personal stories, workshops and networking with other parents with children who have similar diagnoses. Everyone was so understanding and compassionate. Then I discovered that each state and large city has an affiliate group with monthly meetings where doctors or social workers speak on topics related to the illnesses or needs of their consumers (our children). For example, topics include housing, work, insurance and estate planning (what will happen to our loved one when we're gone?).

NAMI has grown exponentially since that first meeting I attended, and since then my husband and I have been to conventions in Washington, D.C. (including advocacy for the mentally ill while meeting at our state senator's office), Boulder, Colorado at the University, and in Dallas, Texas. Another area of involvement for our family is the sibling support group. When Jim was first diagnosed, our family all dealt separately with their own issues with their brother. Our three oldest sons had graduated from high school and were off at college or finding their way in life, so they did not witness or experience the daily trials and tribulations of Jim's behavior. We, as parents, "walked on eggshells" while dealing with Jim for those early years. But, with his steady improvement, we are "normal" again, in our relationship with him, as are his siblings.

Jim plays a good game of bridge. For example, one family in particular, loves to include him for a quick game. When we have a family vacation or family gathering during holidays, his nephews and nieces love to play cards or games with him and he's almost always willing.

As far as his social life is concerned, Jim prefers the friends he has made through the mental health organizations rather than his old school friends. I think he feels more comfortable with those who have experienced a similar illness. Maybe this attitude comes from the stigma involved in mental illness. We have found that the best way to deal with stigma is to meet it head on. I feel free to discuss Jim's schizophrenia with anyone. As a result, several parents have

> approached me to ask for help or advice in dealing with a family member who needs help. It has been very satisfying to be able to empathize with someone who is hurting and confused. We've been there. Openness is reciprocated and helps ameliorate stigma through knowledge and understanding.
>
> As we age, we must plan for our son's future. After twenty-five years, Jim has stabilized with his medication to the point where we feel that he'll be able to cope with life on his own. He also has a marvelous peer support group in an organization of over one hundred families. Estate planning is an essential part of long term planning. Having five siblings, Jim will have family emotional support as well. We feel confident that they will be there for him when we're gone. We have discussed this subject at our family meetings that we try to have every year: We have combined a vacation with time for meetings where we discuss family issues. The process has drawn us all closer and developed real friendships among our children – a very rewarding experience.
>
> **"We've told our story to give you, the readers, hope that there is light at the end of the tunnel. Our journey continues!"**

Overview

This personal story demonstrates clearly what Kenneth Terkelson from Cornell University Medical Center in New York described as a "pattern of family response" to mental illness in a close relative. The pattern of response involves ten stages.

Stage I. Ignoring What is Coming

You usually notice unusual behaviors or notice that "something is wrong", but you do not appreciate that the psychological disturbance or behaviors may be early symptoms of mental illness. Instead, you think that the disturbance or behaviors are temporary and will pass with time. Some of you may have periodic anxiety but you seek no professional guidance.

Stage II. The First Shock of Recognition

This phase occurs when you recognize the signs and symptoms of the mental illness. This occurs long before a formal diagnosis is made. During these undiagnosed years, the mental illness may affect many aspects of family life: work, leisure, finances and family relations. Usually the first persons to notice that something is wrong are parents. Unlike professionals, parents have known their child for years, and therefore, notice subtle change in moods and behaviors.

Stage III. Stalemate

In this phase the consumer rejects helping efforts and refuses any offers of assistance from you. In fact, some consumers will demonstrate less problematic behavior and actually improve in their social and work function so as not to let others know about their illness. Meanwhile, you become more anxious and conflicts may arise. This is a frustrating phase for you because you no longer ignore the problem; yet, unless the consumer is a child or adolescent, you are powerless to do anything about the problem. The exceptions are when the adult consumer is suicidal, homicidal, aggressive or has bizarre behaviors. In these cases, you should call the police.

Stage IV. Containing the Implication of Illness

You adjust to the illness, becoming entrenched in your own thoughts about mental illness and your actions to manage it. Household routines are upset; family life is disorganized; and many of you wait in fear, anticipating another episode of illness. When you know that something is “very wrong” this knowledge affects your current experiences that range from shock and disbelief (i.e. “how can this be happening to my bright, vibrant and successful child?") to self-blame (i.e. "I always knew this person was different but I didn't do anything about it!").

Stage V. Transformation to Official Patienthood

When a family member is formally diagnosed with a major mental disorder, it becomes an important family milestone because it provides you with a medical framework for obtaining information about the illness and moving forward. The consumer moves forward in the role of 'consumer', you may move forward in the role of 'primary caregiver' (see our next Chapter), and your whole family goes through dynamic changes. Sometimes this stage occurs when the consumer is hospitalized because of suicidal, homicidal, aggressive or bizarre behaviors.

Referring to her sister's hospitalization, Victoria Secunda, author of <u>When Madness Comes Home, writes:</u>

> **"Something inside me snapped as the reality of my sister's madness and its implications took up permanent residence both in my disbelieving mind and in my relationship to her. Mental illness came, that day, the invisible, uninvited third party in what had previously been a sibship of two. And with this phantom presence, my calculus of our family and my sense of safety in the world collapsed."**

Stage VI. Search for Causes

Once you accept the psychiatric diagnosis, you and other family members can move forward from denial to awareness. You then think about the <u>cause</u> (or causes) of the mental disorder. You ask yourselves "why does ______ have the mental illness?" You attribute *blame to someone* (i.e., yourself, spouse, another family member, or someone outside the family) or your attribute *cause to something* (i.e., heredity, chemical imbalance, substance abuse or "something going wrong" during pregnancy or delivery, God's plan, or chance). These thoughts are strong influences on your behaviors. For example, you may not share your thoughts about the cause, especially if you blame yourself. Or, you blame more than one cause for the mental illness. For example, one of our family members blamed inheritance ("we have a history of mental illness in our family") and a biological cause ("a chemical imbalance in the brain") for mental illness in her daughter. Lastly, these thoughts are not fixed or rigid; they change over time as you learn more information about the disorder

Stage VII Search for Treatment

In this phase, you gather a lot of information about the diagnosis and treatment options of the specific mental disorder because it helps you to better evaluate the situation and to make informed decisions. Information about the illness and its treatment is found in books, professional journals and on worldwide web sites. Local resources include community mental health centers and treatment centers in universities. You are better able to help the consumer (and yourself) when you understand the nature of the illness**.**

Stage VIII. Collapse of Optimism

This phase usually begins when you realize that the consumer has only partial or no response to treatment. It becomes apparent that the consumer is not returning to his/her previous level of function. If you haven't yet, you now go through a grief process that is very similar to that experienced when someone dies. Much research in grief indicates that you will go through three phases of grief: 1. Shock and Disbelief, 2. Anger and Sadness, and 3. Coming to terms with your loss.

Stage IX. Surrendering the Dream

Unlike the death of a loved one, you realize that the mental illness is not going to go away and that you must make some adjustments. In this phase, you realize that you to include the mental illness into your life.

Rather than trying to save the past, you look forward to the future. You reduce expectations and set more realistic goals. Eventually, your adjustments begin to feel "normal".

Stage X. Picking Up the Pieces

In this last phase, you begin to take care of yourself. Those who cope best use multiple strategies, sometimes all at once. (Practical advice is offered in Chapter 15)

While Terkelson's pattern involves ten stages, no family proceeds through the series of these stages in a lockstep fashion or at the same pace. For example, changes in the illness, hospitalization or family events influence your pattern of response. In fact, Terkelson noticed that many families stepped back to a previous stage when a crisis developed. You may have periodic and repeated grief reactions when a crisis occurs (such as a rehospitalization) or you are reminded of "what was" or "what could be" (such as on birthdays or anniversaries). If the grief becomes a "chronic sorrow" you should seek professional help. In our own family studies, about one-half of the family members were optimistic about the future well being of their mentally relative. Also, feelings of optimism and pessimism varied with time. Families who were in the early years of the illness were more optimistic than families who dealt with the mental illness for many years.

The Family Life Cycle

In 1989, David Olson and colleagues presented seven stages of the family life cycle; each stage presents its own worries, concerns and challenges. These stages are presented in the Table.

- Young Couples Without Children
- Childbearing Families and families with Preschool Children
- Families with School-Age Children
- Families with Adolescents in the Home
- Launching Families (adolescents are beginning to leave home)
- Empty Nest Families (absence of children in the home)
- Families in Retirement

Clearly, family demands, concerns and tasks when adolescents are in the home are quite different from those of a family in their retirement stage. However, the stress of a mental illness in any family member puts an additional stressor on family dynamics during all of these stages. For example, when we interviewed parents of mentally ill adolescents, they were most worried about future academic and schooling issues. In contrast, older parents in their retirement stage were considering issues such as estate planning. These older caregivers worried about the future, especially when they could no longer provide supervision due to their own illness, death or disability.

Should My Family Seek Professional Help for Themselves?

While there are no clear guidelines for determining which families could benefit from professional help, most family members know when their family is not functioning well. F*amily burden,* defined as the emotional, social and financial stresses that mental illness imposes on the whole family, usually increases family tensions and can break some families apart. Usually, if a family functions "well", this means that it has strengths and resources to get through everyday life and adjust to the more difficult times. While the mental illness can stress relationships, the functional family remains intact and finds ways to manage the illness. For example, a functional response would be getting outside help. In contrast, a dysfunctional family has limited strengths or resources to get through everyday life. Most dysfunctional families do not have the strengths or resources to get through the difficult times imposed by a serious mental illness. Many do not get help.

As a guide to answering this important question, we ask you to consider whether your family has serious problems in <u>several</u> of the following areas. If so, we encourage you to seek professional guidance.

- **Emotional Overinvolvement** Sometimes families become "too involved." Perhaps the most prominent data on this subject is related to consumers with schizophrenia. Studies show that those consumers who live with relatives who are highly critical or emotionally over-involved (high expressed emotion or high EE) have a higher probability of relapse than those consumers who live in lower EE households.

- **Unable to solve problems** The family is unable to find solutions, resolve problems or act on decisions.
- **Communication problems** Family members do not talk directly with each other and do not discuss feelings openly. Signs of problems in this area are frequent quarrels, annoyances and sometimes threats.

- **Problems with Roles** The family does not have established patterns of behavior for handling family tasks. Signs of problems in this area are when family members do not know what is expected of them, household tasks are not shared and people need to be reminded to complete tasks.

- **Relationship Problems** Relationships are strained and tense. Family members are reluctant to show affection for each other.

- **Behavior Control Problems** The family does not adhere to any rules of conduct and does not maintain standards for the behavior of its members. Signs of problems in this area are that members do not know what to do in an emergency, members hit each other, and the family has an “anything goes” attitude.

8

Psychiatric Stigma

"… The moment the label of mental illness is applied, its primary side effect and complication-stigmatization-sets in"
Victoria Secunda, When Madness Comes Home

My Brother

When I was in eighth grade and, the younger of my two brothers, was a sophomore in college, he was diagnosed with Bipolar Disorder. Bipolar, formerly more commonly known as Manic Depressive Disorder, is a severe imbalance of brain chemicals causing intense cycles of debilitating depressions and out of control manias. For the past five years, Tom has fallen into depressions so deep that he has literally been unable to get out of bed, then suddenly and without warning, he will shift to an on-top-of-the-world high. At the age of thirteen this was impossible for me to understand. The person who had truly been my best friend for as long as I can remember, had utterly disappeared. I don't think that anyone could understand this unless they have watched it happen to someone they love, but Bipolar completely changes the personality of the person that it catches hold of I can look at and literally not recognize him. There is the old distant in my memory that I will never forget. A brother that doubled as a friend, a brother who I accompanied on his paper route, a brother who happily and excitedly drove me wherever I wanted to go as soon as he got his license, a brother who didn't make me sad when I thought of the days he had encountered in his past. Tom's illness has forced me to grieve the loss of, while he is still in my life everyday.

At first I didn't know how severe the disease was, and I was completely unaware of how it would change his life and my life over the next couple of years. When Tom took his medicine, he was fairly normal and able to do everyday things, but as soon as he felt normal and healthy again, he would stop taking his medicine, thinking that he didn't need it to function and not wanting to believe that he was dependent on mass amounts of chemicals. Thus began the wicked cycle that would fill the next five years of my family's life. Tom would take his medicine, be seemingly healthy, and then we could literally watch him cycle down into an agonizing depression because he had stopped taking his medicine. This was one of the most painful things I have ever had to witness. I can't describe what it is like to sit on the edge of someone's bed, willing to do anything in the world to make them get up, anything to make them not sad anymore, but to have no power whatsoever to do so. But perhaps what is even sadder is the fact that my family has suffered in silence for years. Because of the enormous stigma our society places on mental illness, I have shared the fact that my brother is sick with no one. Despite the fact that I have some of the most trustworthy friends around, I haven't found the strength inside of me to tell anyone. Honestly, I was scared that my friends would think that my brother was a freak and in turn not want to be around me. I was scared that my friends just wouldn't understand, that they would believe the common misconceptions that our society has about people with mental illness: that they not only have a character flaw, but are dangerous to society. But most of all, I think that my parents and I have been so secretive about Tom because we didn't want him to get hurt. We didn't want people knowing things about him that they could potentially use to hurt him. The bottom line is that telling someone that your brother has Bipolar Disorder is much different from telling them that he has diabetes or cancer. There's something much scarier and unknown to people about mental illness, something that only education, awareness, and experience can fix. Looking back on the first couple of years that my brother was sick, I can honestly say that I dealt with him and the situation my family had found itself in with more maturity and grace than I have dealt with anything else in my life. I somehow found the clarity to realize that my brother was indeed sick, and I was somehow able to accept that, something I am often unable to do now. Perhaps one of the most difficult things I had to accept was the fact that my brother needed my parents and their attention more than I did, despite his older age. But as the years passed, it became harder and harder for me to deal with my brother in a graceful and mature manner.

By the middle of my junior year, I was completely exhausted and fed up with my brother and everything that came along with him. I am ashamed to say, but that year, and even into my senior year, my behavior towards my brother was as cruel and mean as anyone could imagine. I said more hateful things to him than I ever said to anyone in my life. I said things that he never would have said to me, that no one should ever say to anyone. These words were the manifestation of so much frustration, anger, and hurt that I had kept inside of me for so many years. The worst part about it was that everything that I said to him I pretty much meant. When I cruelly told him I hated him, I was being honest...but I didn't really hate *him,* it was more like I hated everything that he had taught me, and

> shown me, and that I had come to realize because of him. I hated him for making my parents feel weak. I hated him for making me upset, worried, sad, and angry all at the same time. I hated him for not being the brother I grew up with, for morphing into a person who I could sometimes barely recognize. The bottom line was that I was seventeen and wasn't mature enough or unselfish enough to face all of Tom's problems. This is where the love part comes in. Despite all my anger and sadness, I loved my brother unconditionally. All the times when I told him that I hated him, I never for a second didn't love him. I still can't say that I exhibit all the patience and kindness towards Tom that I wish I could, but I can say that everyday I make a genuine effort to treat my brother the way I know he would treat me. It took a lot of meanness on my part, but I was finally able to step away from myself and see what a horrible person I was capable of being. I guess I finally grew up and realized that the person I was hurting was the same person who I know would do anything for me. The same person who, when I call him and tell him I'm having a bad day or feeling sad, acts as if he's just been told the most heartbreaking news in the world, and it is the same person who I've always loved and respected more than anyone. Sometimes, though, it was hard for me to believe in love because my family and I have learned that all the love in the world couldn't conquer or beat or even begin to fight Bipolar Disorder. Our love for Tom did, perhaps, catch falls, but it sadly could never compete with the disease.
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> Now I know that I can love the new Tom as much as I loved the old one, perhaps a little differently, but with no less devotion. What I've learned from this is that a family is like a pond...the ripples of what happen to one member are bound to reach every other member. If you throw something big and heavy into the pond everyone will feel it. The ripples from everything that was happening to washed over everyone in my family. Because of this, every time Tom was hurt or scared, a little part of my heart broke, and a little more of me ached with his pain. And, every time anyone in my family was hurting or was sad because of what we were going through, the others had to be a little stronger, and we had to love each other a little more so we could survive it.

Overview

Persons with mental illness are stigmatized. They are characterized as "abnormal", "substandard" or "'undesirable" because of their illness and people treat them differently. Their stigmatization includes devaluation or "looking down" on them. This stigma is especially linked with fear of unpredictable behaviors and violence. Although small in number, media coverage of gruesome, dangerous or violent acts by consumers contribute to society's fear of the mentally ill.

When Stuening and colleagues (1992) interviewed over 1,000 adults living across the United States, they found that mental illness carried great social stigma. Thirty years later this phenomena of stigmatization continues and studies indicate that it extends beyond consumers to their family members. .

What are the Effects of Stigmatization?

Social distancing and social avoidance- you may experience social distancing by other family members, friends or co-workers. You react to this social distancing by covering up about the illness, feeling unable to have visitors at home, isolating yourself and not knowing how to explain mental illness to others. If you are a spouse, social avoidance may be especially problematic because you have the same social contacts as your spouse with the mental illness.

Hiding the Illness or Hospitalization -- It is especially difficult to hide the illness when symptoms include bizarre behaviors, which become evident to friends, neighbors or coworkers. Also, when a hospitalization occurs it usually requires your time away from work. When Dr. Phelan and colleagues (1998) surveyed 156 parents and spouses of first-admission psychiatric consumers, they found that most family members did <u>not</u> perceive themselves as being avoided by others because of the hospitalization. However, like the sibling in our personal story, half of them did report that they tried to conceal the hospitalization, especially if they did not live with the mentally consumer.

Ethnic differences--Ethnicity plays a role in how you perceive stigmatization. You may be more likely than others to take care of your immediate and extend kin. You expect to be called upon to provide care in difficult situations and you will offer help more readily than others.

Coping with Psychiatric Stigma

To quote our parental contributors:

> We have found that the best way to deal with stigma is to meet it head on. I feel free to discuss Jim's schizophrenia with anyone. As a result, several parents have approached me to ask for help or advice in dealing with a family member who needs help.

A recent study of over 400 caregivers (Struening, 2001), showed that it is the *perception* of being rejected that makes life even more difficult stigma for caregivers and families. Therefore, we advise that you acknowledge and accept your concerns about stigma. If your problems persist, consider seeking professional help.

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THE PRIMARY CAREGIVER

My Husband

My husband is bipolar (what used to be termed manic-depressive). I have not read books on the subject, only articles from time to time. Also, I have not talked with my husband's therapists to any great extent. Any conclusions I have reached are my own observations after my nearly forty-five years of living with a bipolar husband. I do not pretend to be an expert or authority on the subject.

Our problems crept up on us insidiously. We had five years of marital bliss. Shortly before our second child was born, I noticed my husband suddenly seemed to require an abnormal amount of sleep. When home, he slept all the time, and he resisted anyone trying to rouse him. I worried. Would he be able to wake up and take me to the hospital if I had the baby in the middle of the night? Of course I didn't think manic-depressive, or anything like this. I did have the baby in the middle of the night and my husband did take me to the hospital. All was well. The demands of the new baby seemed to correct the sleep disorder. I promptly forgot my alarming thoughts. Sadly, this was the beginning of a lifetime pattern characterized by swings from crippling depressions to manic states with periods of normalcy between extremes.

My husband's depressions are crippling. He lies in bed, but claims he does not sleep. He cannot function in this state of mind. There seems to be no one event that triggers a depression, though I can usually see it coming on. There are small clues. He is less talkative and more reclusive. I notice him fighting the enveloping feeling. Finally, he succumbs, and invariably starts to drink. I try to cut out the drinking in this phase by getting rid of anything alcoholic and hiding all car keys, credit cards, money and checkbooks. At best this is a temporary fix. My husband can be even worse to deal with sober, and he still can't function. Initially, he sounds more rational when you converse with him, but he perceives most anything you say to be hostile and he often becomes combative and verbally abusive. In a deep depression, my husband says he feels suicidal. When I bother him, he says he's having a nervous breakdown, and he pleads with me to leave him alone. Sometimes he threatens to take an overdose, or jump out the window. I don't take these threats seriously any more because, in all these years, he's never attempted suicide. While depressed, he eats hardly anything, and only in the middle of the night when everyone else is sleeping.

The depressed moods are frustrating to say the least. When the depressions become so severe that my husband takes to his bed, I feel very depressed too. I guess it's not clinical because I still function. It's definitely not a fun time for me. This is the situation where it's better to keep away and detach. I take too many risks trying to reverse the cycle. It just seems like I have to try when there is something important he needs to do, such as go to his doctor's appointment. Or, he may have promised me he'd do something, and I can't resist trying to make him do it, even at the risk of eliciting his rage. A depressed state may go on for weeks, or months. Once, it was over a year.

Somehow, we got by. I hated calling work and reporting him ill because I felt I was lying. Now, I know I wasn't. He was ill. Another mistake I made over and over again was to promptly forget a depression once my husband recovered. I was sure it was an isolated incident that would never recur and life began anew. Maybe it was my inborn optimism. For whatever reasons, I hid my head in the sand for years. Denial seemed much easier than acceptance. The embarrassment and social stigma attached to bipolar disorder makes the spouse and family members almost afraid to admit the truth even to themselves.

If we had been independently wealthy, life would have been easier. The constant worry about my husband's job dragged me down. I felt a responsibility toward my children. Somehow I had to get them through, at good schools, in a decent house and neighborhood. My husband lost most of his jobs. Although his first company didn't fire him, my husband's employers kept asking him what he might be willing to do. When he repeatedly did nothing, they finally laid him off. The periods in between jobs were excruciating. Whenever he lost a job, he'd go to bed and do nothing for a seemingly interminable time. Eventually, after I came to the realization that the bipolar condition was permanent and that my husband would always have these so-called "lows," I did get a job and helped to support my family for twelve years.

When the depressions subside, usually quickly, my husband typically has good periods and functions normally. These periods were quite sustained in the early years. Life is delightfully normal at times. Then my husband starts to steam up, his pace of life accelerating as he takes on more and more responsibilities and promises to do more and more things for more and more people. Sometimes, the manic phase becomes extreme. Extreme manic phases make me nervous and apprehensive. My husband is like a tinder keg poised to ignite. Try as I do, everything I say riles him up and intensifies the mood. I can't just be silent and detached. He talks constantly in these states, and he wants, even demands a response from me. There is no way of predicting how he will react, or what he might do. I worry. Will he take off in a fury? Will he throw things and slam doors? Suppose he spends all our money? He has a myriad of ideas for rearranging the house and everything else. It is wise not to thwart his ideas at this point, but I just can't reorganize my habitual ways of doing certain tasks that I have completed successfully in my own way for many years. This arouses his anger. He accuses me of being the whole problem because of my negativity and because I don't support all the ventures he's dreamed up to make us rich. We argue a lot when he's in this kind of mood.

Needless to say, it has been difficult to achieve serenity in my life. My husband really has three different states of being: the depressed, the manic and the in-between normal. It's hard to plan anything involving him because you just don't know what state he will be in when the time comes. I feel I've lucked out with most of our trips. Also in both depressed and manic states, my husband shows little responsibility to anyone. He has little either knowledge of or respect for our financial limitations. He doesn't meet commitments. I have often been in the uncomfortable position of trying to explain away his lapses and his inability to meet deadlines or fulfill commitments. Now that he's retired. I encourage him not to commit himself at all. It's easier this way.

My story would not be complete without adding that my husband, when on the beam, as I call his normal state, is a good husband. We are very congenial, and we have fun with each other. He is very smart, and he is well read, a good conversationalist and an interesting person. We've had many wonderful times in our life, and I feel we have never stopped loving each other. There is just this lingering problem which will probably never get better. I try to handle everything I can, and only involve my husband when there is no other way.

Looking back, it is evident to me that when any husband and wife are as intensely bound up with each other as we are, the illness of one has an emotionally damaging effect on the other. It's even likely that the other spouse, who does not have the disorder, is ill too. I definitely feel I was ill when I was drinking heavily. You cannot successfully deal with a bipolar spouse if you are alcoholic or mentally weak yourself. Both the manic and the depressed states require too much from you. At these times you must be ever vigilant and careful about everything you say or do in any communication or interaction with your spouse. Of course no one is perfect, and I have to admit that I am stubborn and headstrong. Too many times, I say or do the wrong thing, and it backfires on me every time. I really feel that professional counseling would have helped me. It could have taught me to control my own emotions. But I was too proud, and, a generation ago when our children were growing up, there was a stigma attached to seeking professional help. And, of course, professional help costs considerable money, which we did not have.

As I see it, the only salvation for the spouse that does not have the illness is for this person to detach from the afflicted spouse, and make a life for himself/herself that is independent of the spouse with the syndrome. When I stopped letting myself get involved emotionally, I started to get better. I think any spouse of a manic-depressive needs to develop this independent mindset, have a career and a life outside the life with the bipolar spouse. When you are married to a manic-depressive, you have to be the one in control. Though your spouse may help you sometimes, you cannot count on it. You must learn to manage your life alone, only benefiting from your spouse's help when he or she is willing and able.

My life has been a patchwork of trial and error to get through and stay married to the man I care for and promised to love "in sickness and in health." The only regret I have is that I could not figure things out sooner with the possible result that I might have maximized the good periods, and perhaps ameliorated or shortened the "down" times. I am pleased that bipolar syndrome is better known and understood today. Articles and books are promulgating an awareness of the disease. It is less of a stigma in society. More research is being conducted, and, hopefully, researchers will figure out the chemistry of the brain to the point that corrective medications will eradicate the disease altogether.

There are a number of conclusions that I have drawn from personal experience. The spouse must have good mental health. The spouse needs help if he or she does not. The spouse, more likely than not, has to have a career and make the money to support the family. The spouse must be strong and be able to subjugate his/her own emotions when the other spouse is in either a manic or depressed state. Most spouses need outside help with this. The spouse must try to get the bipolar spouse to a professional at the first sign of the disease, just as he or she would if a physical problem developed. The "normal" spouse must be ready and willing to accept the diagnosis and support the recommended drug therapy. If I had followed this path from the beginning, I might have had more good years. Group therapy specific to the disease might have helped me. People who live with a bipolar person surely have something to say. I'm sure I could have benefited from hearing about their experience with the disease and how they coped. If I had shared my experiences and observations, I might have helped others.

My story is not over yet. It probably will continue for the rest of my life, or my husband's life. I have not solved the problem of bipolar syndrome. Maybe science will find the cure some day. I always thought I was an intelligent person with good common sense. It takes more than this to tackle the problems the bipolar disorder can bring to the family. I regret that I did not wise up sooner and seek help for myself. It takes too long to figure it out alone. Good years are wasted on this exhausting, never-ending quest. Anyone married to a bipolar must accept it, and stop covering up and making excuses for his or her spouse. Forget what other people think. Get whatever help you can afford, even if it's a free clinic. Find others who have the same problem in their families to converse with and share experiences and possible ways to improve the situation that is confronting you. I have had some wonderful times with my husband. I'm still glad to he married to him. But I hate both the depressed and the manic cycles of his illness. It's so hard to live with someone who changes on you. If he was same good man all the time, how happy we would be. We could even argue and fight just like normal married people.

Conclusion: All is not lost. There is hope.

Bipolar syndrome is a horrible disease, but there are ways to manage the disease which can improve life for the whole family A happy and satisfying life is still possible with the right approach and outlook. It takes a lot of hard work, perseverance, and an incredible amount of patience. There is hurt and pain that everyone involved has to endure. But it's worth the effort and the suffering when the reward is big dividends in enjoyment of life. There is perhaps an unevenness to life, but I ask myself, "Is anyone's life continuously even throughout?" I'm happier now that I have a handle on the disease. I have less anxiety than I had in the early years. And, of course, there are always the good times when my husband is stable. I look forward to these times, and I am thankful there are still more

> good times than bad. I think I can include my husband and say we both cherish every trouble free day we have together. It is my sincere hope that the conclusions I've come to after many years fraught too often with anguished struggle will help someone else whose spouse, or child, or anyone in the family, is a manic-depressive.

Understanding the meaning of caregiving

This personal story reflects three dimensions of caregiving (Gonache, 1994):

1) **"care"** - assistance with daily living, money outlays,
2) **"control"-**efforts to prevent drug abuse, violence, and embarrassing acts, and
3) **"worry"-**concern for the mentally ill person's welfare.

Studies show that caregiving responsibilities are not equally distributed throughout families. Usually, one person, called the *primary caregiver*, takes most of the responsibility for the mentally ill person's welfare. Typically, the primary caregiver has the most frequent contact (usually, at least twice a week), lends financial support and is frequently involved in supervising daily activities and treatment. In many cases, primary caregivers are parents but anyone (spouse, sibling or child) could assume this role. Most often, primary caregivers are women and mothers.

While caring for a person with a severe mental illness can bring some gratification, primary caregivers experience difficulties as they try to adjust to the severe symptoms and problem behaviors associated with the mental illness. The term *caregiver burden* is used to characterize the level of distress that the mental illness places on the primary caregiver. Our studies indicate that mild levels of burden and distress can mobilize many caregivers into constructive actions and make for a positive care giving experience. But, moderate or severe levels of burden and distress can immobilize many caregivers and make for a negative caregiving experience. Eventually, caregiver burden can express itself in some form of psychological distress, social disruption, physical illness or economic hardship.

Psychological Distress

"It's intensely painful to see a loved one suffer from the desperate bleakness of major depression, and just as painful and frightening to see him or her in the frenzied grip of mania." Mortimore

The day-to-day supervision and oversight of a mentally ill family member is difficult. It often includes distress, worry, guilt and confusion. Studies show that more psychological distress is associated with being older and being in a lower socioeconomic group. Also, many primary caregivers experience severe psychological distress when the mentally ill family member is hospitalized, demonstrates violent or suicidal behaviors, or demonstrates negative symptoms of schizophrenia.

Social Disruption

Taking care of the mentally ill person can disrupt what used to be the normal social activity of the caregiver. Some caregivers have to work part time to get extra income; others have to give up jobs to lend supervision. Others limit their household tasks or become socially isolated from friends.

Physical Illness

Sometimes the stress of mental illness in the family accumulates and affects the caregiver's physical health. Studies indicate that caregivers under severe distress have psychosomatic illnesses, such as ulcers or high blood pressure. Often, caregivers are so focused on the consumer's care that they neglect their own health and medical care.

Economic Hardship

Society's view of mental illness is also reflected in the public's reluctance to pay for mental health services. Insurance companies usually limit their coverage for treatment of mental illness. Many families are often left paying for needed mental health services. Also, many individuals with schizophrenia, bipolar disorder and depression become "disabled" or lose their jobs. Others can work only part time, or they are forced to work in unskilled jobs. These work-related problems cause financial hardship on the primary caregiver and other family members.

Caregiver Concerns

Linda Rose (2002) from The Johns Hopkins University School of Nursing interviewed the primary caregivers of 15 consumers who had been diagnosed for at least 4 years with major depression (N=4), bipolar illness (N=6), and schizophrenia (N=5). Her caregivers included 5 spouses, 4 parents, 2 adult children and 4 siblings. While the caregivers were different in many respects, this researcher identified three major themes or caregiver concerns, which are briefly described in the Table:

Staying connected*: finding the essence of the person obscured by the mental illness.* Caregivers have a need to see the consumer as a "son" or "daughter" or "mother", etc. In other words they did not want to lose sight of "the person beneath the illness".

Finding a place for self in influencing the illness*.* Caregivers strive for control and develop routine responses to illness-related behaviors. They believe that their responses can actually make the illness better or worse.

Helping the relative to move forward*.* Caregivers try to be realistic about the future. They set goals for the consumer, revise these goals if necessary, and generally express "cautious hope" for the future.

Do I Need Professional Help?

If you are a primary caregiver, our studies indicate that mild levels of burden and distress can mobilize you into constructive actions and make for a positive experience. However, moderate or severe levels of burden and distress can immobilize you and make for a negative experience. In our studies, about 50% of primary caregivers reported symptoms of depression or anxiety that could be clinically significant, meaning that they should get professional help for their symptoms. We encourage you to seek professional help when your depression or anxiety interferes with your ability to function normally, when you become socially isolated, or when you neglect yourself.

How Can the Rest of the Family Help?

Family members should offer to share in or help with some aspects of caregiving. Three very practical tips include:

1) Ask the primary caregiver this question: How can I help you?
2) Help monitor consumer safety and dangerous behaviors, and
3) Provide respite time so that the caregiver can do something special for themselves.

Part III
HELPING

10

Professional Treatment Options and Clinical Trials

Outpatient Treatment

Most individuals with Depression, Schizophrenia or Bipolar Disorder are treated in outpatient facilities, which include private physician or clinician offices, treatment programs within hospital systems, and community mental health centers. In most settings, you are not usually involved in treatment. However, a treating physician or clinician could involve you (with the adult consumer's permission) in the assessment process to gather information) or in brief meetings to clarify or work through an issue. If you are invited to a meeting, you should:

- Prepare for the meeting and keep your appointment.
- If there is any medical information that you have, take it with you .
- Tell the staff your impressions about how the treatment is working.
- Openly discuss your reactions and concerns. Ask questions.
- Make sure you have an emergency number should there be a crisis. during off-hours

Psychotherapy

Physicians will often recommend psychotherapy in addition to medication treatments. Psychotherapy involves a meeting between a clinician and the consumer (or group of consumers) to help the consumer cope with their illness and the effects of the illness on their life. Psychotherapy can be individual, group or family.

There are many types of psychotherapy; they range from highly structured types to very unstructured types. Two well-studied types of psychotherapies include:

1. ***Interpersonal therapy***-this type of therapy focuses on relationships. Often the illness places a strain on relationships that the consumer has with others in their life (friends, spouses, children, co-workers, etc.).
2. ***Cognitive-behavioral therapy (CBT*)**- this type of therapy focuses on identifying and changing pessimistic thoughts and beliefs that influence behaviors. While it is not a treatment of choice for persons with Schizophrenia, recent research reported by W. Bradshaw from the University of Minnesota, indicates that long-term outpatient CBT may lend to significant improvement in symptomatology and social functioning. Research in this area is continuing.

Inpatient Hospitalization

Most of the time, consumers with major mental illnesses can manage outside a hospital. However, if they experience a serious, “acute episode”, they may require inpatients hospitalization. In a 1993 family survey of over 3,000 families in the National Alliance for the Mentally Ill (NAMI), Agnes Hatfield and her associates at the University of Maryland reported that more than 60 percent of their mentally consumers were hospitalized in the last two years.

We have listed in the next Table, our recommendations of when, despite consumer protests, you should notify a professional and consider hospitalization for your relative :

Consider hospitalization when your relative:

- **Is suicidal or homicidal,**
- **Is aggressive, impulsive or unable to control their behavior,**
- **Requires round-the-clock care and support which is impossible for the family to sustain,**
- **Is abusing drugs or alcohol, has an unstable medical condition, and**
- **needs medication adjustment and/or close observation of their reactions to a new medication.**

Consumers with Bipolar Disorder are often hospitalized during a manic phase of their illness because they lack insight and judgment. Many depressed individuals are hospitalized because they are seriously thinking about suicide or have tried to commit suicide. Individuals with Schizophrenia are hospitalized when they are aggressive or hear voices that command them to hurt themselves or others. Substance abuse and medication nonadherence (See Chapter 14) often lead to hospitalizations.

What can I expect during the hospitalization?

During the hospitalization, you will experience changes in your everyday life. Hospital visits need to be incorporated into your daily routine. Because all hospitals operate differently, you should receive (or ask for) a description of the inpatient service, visiting hours and hours of physician and social worker availability. If your relative agrees, you should expect to work closely with the inpatient treatment team especially if the patient lives at home. If the patient is a child or adolescent, you should expect to work closely with the treatment team.

Sometimes you are the most reliable source of information and may be asked about events prior to the acute episode. Also, you may have knowledge of any pre-existing medical conditions, nonadherence issues or substance abuse problems. Studies indicate that family attitudes toward inpatient treatment can influence the course of the hospitalization. These attitudes include the family's desire to have their relative return home, the family's resistance to treatment and their satisfaction with the service provided. Some inpatient units offer orientation classes or ongoing family programs to address the family's fears, uncertainties and concerns during the period of hospitalization.

When consumers are acutely ill and need to be hospitalized, they often lack insight. Therefore, we encourage you to talk to your relative about psychiatric hospitalization when they are well. The discussion should include how you will respond when you see symptoms of an acute episode. Despite this discussion, be prepared. First, the consumer will usually object to being hospitalized, may accuse you of interfering in their life, or could become angry or hostile. Secondly, you will experience a variety of negative, neutral and positive sentiments. Negative sentiments include worry, fear, shock, anxiety and depression. Neutral and positive sentiments include approval, relief and hope that your relative will now receive the care they need.

The length of time that you have been managing the illness prior to a hospitalization and the number of prior hospitalizations influence your reactions. For example, in when Madness Comes Home, Victoria Secunda recounts her own feelings when she first hospitalized her sister:

"A sour mixture of deliverance and remorse rose in my throat. I wondered if I was doing the right thing. My heart is breaking. I felt I was betraying her utterly. "

While a hospitalization can be quite distressing for you, recognize that acute episodes are part of these major mental illnesses. For example, the mother in Personal Story B describes a change of her feelings over time:

“That was our first experience with a psychiatric hospital and I felt strange being there, but relieved that Jim was getting some help and evaluation. I felt uncomfortable in the presence of any psychiatrist because I thought everything I said or did was being analyzed too. But that feeling went away gradually as I became more familiar with many doctors through all eight of Jim’s hospitalizations!”

What can we expect after the hospitalization?

Recovery includes symptom improvement and improvement in specific areas of activity. Consumers who are early in the course of their disorder demonstrate different recovery patterns than consumers who have been hospitalized many times. Unfortunately, one of the best predictors of readmission is a person’s history of a past psychiatric hospital admission.

Assuming that you have a good relationship with the consumer who has achieved some level of clinical stability prior to discharge, it is very important that you encourage them to follow the plan for post-discharge treatment and to stay on their medication regimen. *Medication nonadherence* is defined as discontinuing medication without the recommendation of the treating physician. You should be aware that medication nonadherence is relatively common in consumers who have been recently discharged from a psychiatric inpatient unit and, possibly, the biggest reason for relapse (worsening of symptoms).

Activity includes work and school achievement, interpersonal relationships, recreational enjoyment and sexual activity. While you members might assume that symptom improvement would predict improvement in these other areas of life, several well-designed studies indicate that all of these areas are fairly independent of each other. Therefore, you should not be surprised to see some impairment in one or more area of function and slowed recovery in others. Additional treatment to help consumers advance their education, job skills or social skills may be needed after discharge.

What is Partial Hospitalization?

Partial hospitalization defines day, night, evening, and weekend care or treatment program. The term “partial” is used because the consumer does not stay for 24 hours in the hospital setting or treatment center. Partial hospitalization programs go by a number of different names. Some are called day *treatment,* or *day program* or *day hospital.* The term that is used is sometimes determined by legal or financial considerations. Six uses of partial hospitalization programs are presented in the next Table.

1. As an alternative to inpatient care. The consumer needs an intensity of treatment that might avoid the need for hospitalization. It is important to distinguish that “alternative” does not mean a “substitute” for inpatient care. Select partial programs that have immediate access to an inpatient service.

2. As a transitional facility. The program follows an inpatient admission and focuses on helping the consumer return to an independent and productive life in the community. Sometimes, inpatients attend this type of program prior to discharge, to ease the transition.

3. As a rehabilitation facility. The focus is to prevent or erase the social and/or vocational deficits that commonly result from a mental illness. These programs emphasize employment training and social skills training.

***4. As an alternative to long-term hospitalization*.** Consumers who live in the community receive supervision, support and go to worthwhile activities.

5. As a means of diagnostic assessment. The consumer is assessed for psychiatric diagnoses. The program has the advantage of more extensive observation or testing.

***6. As an extension of outpatient treatment*.** Sometimes consumers do not meet the requirements for inpatient care, so they receive more intensive outpatient treatment.

Clearly, there are various types of partial hospitalization programs. Since each program has its unique purpose or emphasis, we encourage you to familiarize yourself with program goals before your relative agrees to attend it or pay for it. Ask whether the program has an evaluation report. For example, does the program evaluate consumers at entry and follow their progress after they leave the program?

The success of the program depends on program goals and the consumer’s commitment to the program. Studies show that consumers who attend day programs or partial hospitalization programs are much less likely to be rehospitalized than consumers who drop out of these programs. Partial hospitalization programs have clear advantages including allowing the consumer to maintain some independent activities, to remain with his family, and to make employment easier. However, partial hospitalization runs higher risk for consumers with assaultive or suicidal behaviors, confused or disorganized thoughts and disoriented behaviors.

Recently Dr. Horvitz-Lennon and colleagues (2001) reviewed 18 research studies published between 1957 and 1997 that compared partial and full hospitalization for the care of mentally ill adults. These researchers found no significant differences in the consumers on measures of symptoms, social functioning, family burden and service use. However, they did find that consumers and families were more satisfied with partial hospitalization in the short term.

Lastly, not all consumers and families have the option of a partial hospitalization program. Therefore, it is important that you check the consumer’s insurance plan to determine whether their policy or provider covers a program. Some programs are “self-pay”, meaning the consumer or family picks up the expenses.

WHAT IS A CLINICAL TRIAL?

A Clinical Trial is a research study designed to answer specific questions about new medications, new therapies or new ways of using established treatments. Before you or your relative agrees to participate in a clinical trial, we encourage individuals and family members to understand:

- why the research is being done
- what will be done during the trial
- what risks and benefits can be expected
- availability of alternative treatments
- contact information
- confidentiality
- any costs
- any payment for participation

Before entering a clinical trial, each consumer or family member that is involved in the study should review and sign a consent for the study. Your signature on the consent indicates that you have been informed about the specific facts of the study. For example, assessments and medications are often provided at no cost to the participant. If you are not offered a copy of the consent, request one.

11

Psychiatric Rehabilitation

You many notice that your mentally ill relative is simply not functioning well in many aspects of his or her life such as social activity, work or family relations. This is because the psychological impairments associated with major mental illness cause decreased abilities in performance or function. For example, a consumer living with hallucinations, delusions or profound depression has limited capacities to work, to socialize or to maintain a home. This consumer cannot meet the role demands of worker, student, spouse, friend or homemaker.

Psychiatric rehabilitation is a focused approach that assists persons to maintain, strengthen or improve their levels of functioning in certain life roles. The focus of psychiatric rehabilitation is on current functioning and future goals. An essential aspect of psychiatric rehabilitation is for the consumer to set personally relevant goals for himself. The consumer's diagnosis does not, in itself, define a rehabilitation program. Rather, staff providing rehabilitation services do an assessment which focuses on two areas: 1) the consumer's skills level and 2) the consumer's environmental supports.

1) *Skills level:* this area involves the consumer's ability to do certain tasks or behaviors <u>in a certain</u> <u>environment</u>. For example, the assessment would determine whether the consumer is able to converse with roommates or persons in a supervised employment situation. Different conversational skills are needed in these two distinct environments. Examples of other skills that are typically assessed include self-care (grooming and dressing), following directions, doing household chores, problem solving skills and job-training skills.

2) *Environmental Support*: this involves whether the living or work situation accommodates or supports the consumer's present skill

functioning. Using our same two examples, assessments would describe the persons, places, things and activities necessary for the consumer to be successful in the community residence or employment situation.

Personnel

A team of professionals trained in rehabilitation counseling, occupational therapy, mental health counseling, psychology or nursing implement the interventions that usually focus on skill teaching and resource development. Skills teaching is often done in simulated environments where persons have the opportunity to practice. Resource development involves selecting a preferred resource, arranging for its use, and assisting the person in linking with the resource.

Employment or Work

Many consumers are unemployed or have limited work skills. Because gainful employment or work is highly valued in our society, it is important that the ability to work or to do work-like activities (such as volunteering or schooling) is assessed. Work or some kind of productive daily activity should be an important goal in psychiatric rehabilitation, especially if the consumer is between the ages of 18 and 50 years, has at least a fifth-grade education, and does not also have a diagnosis of mental retardation.

Most consumers go through a screening process before they enter a job-training program. Consumers perform well in job training programs if they are willing to make a commitment to participate in the program, if they are capable of understanding the nature of the training, if they don’t have disabling symptoms (such as negative symptoms of Schizophrenia or severe depressed mood), if they have previous work experience, and if they have supportive families.

Finding and keeping a job are no easy tasks. The table presents a Social Skills Training three-tier, ten-week approach that was recently described by Hector Tsang (2001) :

Tier I-focuses on Basic Social Skills such as interpersonal communication skills and job survival skills (grooming, politeness, and personal appearance).

Tier II- focuses on General work-related skills that are essential for securing a job (i.e., making a good impression in the initial interview) and for keeping a job (i.e., good relations with a supervisor).

Tier III- focuses on Benefits and Consequences of Having a Job (i.e., salary, social contacts satisfaction from working).

What is the Role of the Caregiver and Family?

Sometimes there is confusion around the essential elements of a good psychiatric rehabilitation program. Sometimes treatment centers present rehabilitation as a goal, but they offer very little in actual service beyond medication treatment and social skill training. Therefore, we encourage you to critically evaluate the overall direction and activities of a recommended psychiatric rehabilitation program.

William Anthony and colleagues from the Center for Psychiatric Rehabilitation at Boston University provide a useful model for evaluation of a psychiatric rehabilitation program. The Table presents eight rehabilitation values that should be reflected in a program's mission and activities.

1. A focus on performance of everyday activities (rather than reducing symptoms or gaining insight)

2. A focus on meeting the requirements of other people in the consumer’s world.

3. A focus on the consumer’s feelings of happiness or satisfaction.

4. A focus on the specific context of where a person lives, learns, socializes or works.

5. A focus on self-determined goals (the consumer is given a choice of placements).

6. A focus on evaluating rehabilitation in terms of the impact on consumer outcomes.

7. A focus on providing assistance for as long as it is needed and wanted.

8. A focus on the improvement in the consumer’s functioning and status.

Lastly, you should form working alliances with the professional staff of the psychiatric rehabilitation program so that goals are clear to everyone. When requested, you can be an excellent environmental support or resource for established goals.

12

Consumer-Run Programs

“Sharing the joy, hope, and wholeness [of my experience] with my peers has been a catalyst to creating a synergistic community of empowered consumers motivated to fight stigma, be politically active and to raise the level of compassion in society.”

Soul in Search of Self: The Lived Experience of Serious Mental Illness by Kimberly Hensley

Consumers, alone or in partnership with non-consumers, are serving as mental health service providers and operate various programs and support groups that generally provide some combination of peer support, education, socialization, information on important resources and advocacy. The emphasis in these programs is the ability of consumers to promote health, define recovery, support the recovery of others, and put into action the principles of good psychiatric rehabilitation.

In this chapter, we describe two models that demonstrate the strength of the consumer self-help movement: The Clubhouse Model and The Recovery Model.

The Clubhouse Model

The Clubhouse Model offers a promising example of partnership between consumers and mental health professionals (Jackson, 2001). Founded in 1948, Fountain House in New York City began a model of psychiatric rehabilitation now replicated around the world (Flannery & Glickman, 1996). Fountain House was begun by a group of ex-consumers from Rockland Psychiatric Center. To support one another, they met on the steps of the New York City Public Library. The original name of the group was WANA (We are Not Alone). The National Council of Jewish

Woman became supportive of the group and helped them acquire a building with a fountain in the back courtyard. As Fountain House grew, the "members" of the "club" decided to hire professional staff to help operate the Clubhouse leading to one of the unique identifying features of the model, a partnership of consumer and mental health professionals. John Beard was the father of the model. The heart of this approach is illustrated by a quote of Beard's from an early video:

> **"I had no interest in why he was sick. That was not my job…I was not interested in trying to review his…psychopathology….I was terribly interested in how normal we could get him to function" (Flannery & Glickman, 1996).**

In a Clubhouse, the identity of being a consumer is discouraged. Medical treatment is supported, but it is to happen outside the Clubhouse. Within the Clubhouse the focus is on strengths and capabilities. Members are partners in the process of their recovery and determine their own goals and participation. Members are involved in all aspects of the operation of the Clubhouse and are empowered by ownership of the Clubhouse and advocating on behalf of the Clubhouse and the Clubhouse community. The foundations of the model are the belief in the power of relationships and community, an atmosphere of respect, mutuality and hope, and the belief that purpose, meaningful activity and work is rehabilitative.

The primary purpose of the Clubhouse is to improve the quality of life of its members. For example, community support is provided, centered in the work unit structure of the Clubhouse, and includes assistance with entitlements, housing, and individual advocacy. One distinction between the Clubhouse model and other forms of psychiatric rehabilitation or consumer groups, is the emphasis on work (Jackson, 1992; Vorspan, 1992). The Clubhouse model is based on the premise that work is rehabilitative. However, unlike specialized vocational programs that require work-readiness, membership in a Clubhouse is open to anyone with a mental illness and is lifelong. There are no time limitations.

The mental health training of the staff (who may include consumers) provides the expertise needed to identify, prevent and support members through times of relapse and vulnerability. Today there are over 300 Clubhouses representing 32 states and 30 countries. The Clubhouse model has been recognized as a best practice by the American Psychiatric Association, and by the researchers working in a federally funded study of the promotion of employment for those with mental illness (Employment Intervention Demonstration Project- SAMHSA, Judith Cook, Ph.D.). Research findings have demonstrated the effectiveness of the model in reducing hospitalization and increasing rates of competitive employment (Beard, Malamud, & Rossman, 1978; Malamud, 1985). Clubhouses report on average a 42% employment rate for members, which is eight times the nationally reported employment rate of 5% for the mentally ill.

The Recovery Model

The Recovery Model is primarily a response by mental health systems to the voice of consumers speaking to what has been helpful to them in their own process of recovery. The Ohio Department of Mental Health has collaborated with consumers, family members, clinicians and program administrators, to develop a "Mental Health and Recovery Process and Best Practices Model" (ODMH, 1999). In this model, recovery is defined as "a personal process of overcoming the negative impact of a psychiatric disability despite its continued presence." The stated goals for those in the recovery process are "functioning at an optimal level and using or providing support to those outside the mental health system." Recovery involves moving from "a state of dependency to interdependency", and to a state of greater awareness of one's condition. The Community Support Program Advisory Committee of the Ohio Department of Mental Health identified nine essential components needed in order for a community to provide effective services and support that are consistent with the goal of supporting the rights of people with mental illness to “live in the community and participate in a lifestyle of their choice”.

The components that are incorporated into the Recovery Model include:

1. **Clinical Care**
2. **Family Support**
3. **Peer Support and Relationships**
4. **Work/Meaningful Activity**
5. **Power & Control**
6. **Stigma**
7. **Community Involvement**
8. **Access to Resources**
9. **Education**

The guiding principles of the Recovery Model are defined as:

- the promotion of self-determination, empowerment, independence, and hope
- the promotion of work and meaningful activity, education, socialization, and community involvement
- a consideration of spirituality and culture, and the needs of the family and significant others
- a consideration of individual needs and variation across the lifespan
- a holistic and integrated approach
- an emphasis on the quality of relationships, and the clinician’s ability to engender hope and trust
- a strength based orientation
- a recovery management plan
- the integration of family as determined by the consumer
- service delivery within the consumer’s community

Which Consumer Group is best for my relative?

Frese and colleagues (2001) discuss the importance of recognizing that consumers (i.e., persons with a mental illness in need of service) vary in their desire for “services”. For example, the degree of mental disability or other coexisting disabling conditions may suggest a better fit with more or less structured interventions or support. Systems are beginning to recognize the various options necessary to provide choice and an individual best fit for consumers.

Currently, a federally funded multi-site study (SAMHSA) is underway to investigate the components and effectiveness of consumer support services. The key ingredients of consumer programs are presented in the next Table.

Empowerment, defined as a sense of personal strength and efficacy, with self-direction and control over one's life.

A belief system including humor, choice, recovery, acceptance and respect for diversity, and spiritual growth.

Consumers as staff, who are hired by and operate the program and decide all policies and procedures.

A safe environment free from threat of commitment, clinical diagnosis, or unwanted treatment, which is accessible, informal and reasonable.

A peer principle that relationships are based upon shared experiences and values, and are characterized by reciprocity, mutuality, acceptance and respect.

The helper's principle that working for the recovery of others facilitates personal recovery.

In conclusion, the self-help movement has encouraged a greater appreciation for the role of the consumer in recovery. Although a necessary and vital component of comprehensive supports for people with mental illness, society also needs to ensure that people with mental illness are not being denied more costly essential services in a system which relies heavily on less expensive alternatives, and provides the array of needed services to those with mental illness.

The consumer movement has offered a greater understanding of the need for the service provider to work in partnership with the consumer, and respect and incorporate the individuality, needs, choices and strengths of the person in recovery. The input of consumers' is vital in the development and assessment of a responsive and effective mental health system. In addition, consumers can become professionally trained providers. Their effectiveness can be enhanced by their personal experience of mental illness, and consumer supports offer a unique and vital community support. Today, consumer programs and groups are recognized and accepted as an integral part of the community support system.

13

Managed Care and Medicaid

> **How to pay for the diagnostic process and the prescription medication was a problem. I think health insurance should cover diseases of the mind the same as it covers physical illnesses.**
>
> Personal statement: caregiver

The delivery of mental health care has changed substantially over the last 50 years. Previously, health care was provided on a fee-for-service basis. More recently, health care reform has attempted to balance the desire to provide the highest possible quality care, with the desire to provide improved access to adequate care at a reasonable cost.

The clinical care provided to consumers by psychiatrists, psychologists, social workers, nurses and other mental health professionals is now managed by a team of administrators and clinicians and this is referred to as 'managed mental health care.' The percentage of care provided to consumers with mental illness in a managed care setting has increased from 50% in 1970 to 90% in 2002

The objective of managed mental health care is to facilitate the quality and utilization of mental health care. Typically, employers limit the amount they are willing to spend on health care, and in particular, mental health care. Employers, health insurance companies, and the government specifically describe the number and kinds of services they are willing to pay for, and then using a team of clinical case managers to monitor the provision of this care. Clinical case managers determine medical/psychological necessity (a clinical service believed to be essential for the diagnosis and treatment for a covered mental illness or substance abuse disorder) and make sure the care provided is a 'covered benefit' (a clinical service provided in the beneficiaries health plan).

There is a defined amount of resources that are 'carved-out' of the general medical benefit for use in the treatment of mental illness and managed in the above manner. The limits of coverage is frequently far below that provided for general medical conditions. For example, the inpatient hospital benefit for a general medical (non-psychiatric) illness usually does not have a limit. Consumers with serious health condition, such as organ transplantation, are routinely hospitalized for treatment as long, as is medically necessary. However, almost all health insurance plans apply limits to inpatient treatment for serious mental illnesses such as schizophrenia, bipolar disorder, and major depressions – typically 15-30 days in the hospital per year.

The following Table lists the five steps built into managed care:

1) **A consumer or a family physician recognizes the need for mental health care.**
2) **The consumer calls the mental health telephone number on the back of their insurance card.**
3) **The clinical case manager (usually a master's prepared counselor) answers the telephone and elicits enough information to determine if a referral to a mental health provider is clinically necessary.**
4) **The clinical case manager refers the consumer to a mental health provider and authorizes a certain number of visits (usually 6 - 8) and the types of visit (usually medication management or psychotherapy).**
5) **The provider meets with the consumer to deliver the authorized care and then calls to seek additional visits if necessary.**

Mental health providers view the above system as frequently inappropriate and unfair, and one of many manifestations of the bias and stigma associated with mental illness.

In 1996, the National Alliance for the Mentally Ill (NAMI) sponsored a survey, which asked its membership about their views of managed behavioral health care. The results indicated that consumers and family members enrolled in managed care plans thought that while *coverage* for non-hospital services (such as crisis management, office visits and family education) was good, access to services and *availability* of services were causes for concern.

Medicaid

Many consumers with major mental illnesses are eligible for service under the Medicaid healthcare delivery system. According to Joel Miller, NAMI senior policy analyst, Medicaid now pays for over 50 percent of public mental health services. He describes that the basic purpose of the Medicaid program is “to provide comprehensive and affordable health coverage, services and benefits to eligible lower-income populations”. Unfortunately, Medicaid programs consume from 15 to 20 percent of state budgets and states are facing serious financial struggles due to rapidly escalating healthcare costs and increasing numbers of eligible persons. Recent Medicaid efforts to control costs include reducing certain types of coverage and reducing pharmacy payment levels. Both efforts have an effect on treatment and medication adherence. Many family members worry about relapse and rehospitalizations. NAMI encourages advocates of the mentally ill to obtain and review Medicaid fact sheets and bulletins developed through their Policy Research Institute.

14

Medication Adherence

Medication adherence is defined as continuing or staying on a prescribed medication regimen. In the past, the terms “compliance” or “non-compliance” were used to refer to this phenomena. Adherence is currently the preferred term as it better reflects the interactive, cooperative environment that occurs in ideal treatment setting. You should be aware that medication nonadherence is relatively common in consumers with Schizophrenia, Bipolar Disorder and depression. Studies indicate that as many as 20-55% of individuals with mood disorders have problems staying on their medication schedules. These rates are even higher for individuals with Schizophrenia.

Medication nonadherence is possibly the biggest reason for relapse or worsening of symptoms. Dr. Paul Keck and his associates from the University of Cincinnati have studied medication adherence over the last decade. These researchers report that 55% of people with Schizophrenia who do not take their antipsychotic medication will relapse over a one year period, compared to only 14% of those who take their medication. In mania, it has been reported that 60% of those persons admitted to a hospital did not take their medication in the month prior to their hospitalization. In Depresssion, 60% of consumers stop their antidepressants; their 1-year relapse rates are 80% compared to 30% for those who take their medication. (Keck et al., 1996)

Predicting who will take their medication and who will not take their medication is difficult. Researchers who study medication adherence report that consumer, illness and environmental factors are all-important influences on medication adherence. Consumer factors such as younger age, single status, male gender and low educational level have been related to medication nonadherence. Some persons stop taking their medications because they feel the need to control their life or have an unfavorable personal attitude towards their physician or treatment providers. Some researchers are studying consumers' belief systems. For example, consumers have to weigh the benefits of taking their medication (being symptom-free) vs. the costs (stigma of taking medication and side effects). Some persons stop taking their medication because they lack of insight, deny their illness, become manic, or abuse alcohol. Some persons stop taking their medication because they experience side effects related to the medication. Others do not live an environment that is supportive or provides adequate supervision or oversight. Some persons do not have family or friends who care about them; they are left alone to cope with their illness.

Practical Ways To Enhance Medication Adherence

1. **Discuss medications rather than argue about them**. Knowing when and how to intervene with medication management is important. You should discuss medication rather than argue about the importance of taking medication.
2. **Be Knowledgeable** . You should be knowledgeable about the time, dosage, side effects and more serious effects of medications that are prescribed. Know how long it will take for the medication to take effect. Remember that some medications take longer to be effective, so you may have to remind your relative of this.
3. **Understand medication response** Some consumers are *full responders* (meaning that the medication is highly effective); others are *partial responders* (meaning that the medication is partially effective) and others are *nonresponders* (meaning that the medication is ineffective at treating their symptoms). Naturally, you want to see a full response and a return to usual lifetime activities and roles. Unfortunately, this is not always the case.
4. **Watch use of other substances.** Drugs (including some over the counter medications) and alcohol can trigger mood episodes and interfere with the effectiveness of psychiatric medications. We encourage you to monitor the consumer's use of nonprescription drugs or alcohol. If he or she has a problem staying away from these substances, families should notify the treating clinician.
5. **Provide prompts to help consumers remember to take their medications.** Rather than reminding (or nagging) the person to take their medications, it is helpful to provide a strategically placed reminder for the medications. For example, some prompts include medication containers placed near meals or bedside, calendars, or post-its.
6. **Participate in educational sessions related to medications.** Some of the programs or organizations listed in our appendix provide interventions or services that are designed to help you improve consumer adherence with

prescribed medication. If you participate, you should make sure that the program or services addresses those factors that are changeable and most relevant to you.

7. **Consider long-acting injectable medications. Consider one daily dosing instead of multiple doses through the day.** These types of dosing are possible with a number of medications.

15

Practical Advice

Be Knowledgeable

Because most mental illnesses are life-long, learn as much as possible about the illness. Realize that there are <u>many</u> theories and opinions about the causes and treatments of mental illness. In fact, some caregivers and family members are overwhelmed by all of the information that is available. Nevertheless, we encourage you to seek out information about the illness from publications, a trusted mental health professional or from a local or national support group for other families with mental illness. Many resources can be found on the Internet. Throughout this section we have included pertinent quotes from the web site page of NAMI of DuPage County, Illinois and from our local family support groups in Northeast Ohio.

Change How You Think

"No one is to blame"

When you understand that the mental illness is not the result of anyone's failings, but it is a legitimate illness that can be treated, many negative thoughts and fears disappear. That is why it is important to be informed about the specific mental illness and ways to manage its most frequent problem behaviors. We suggest that you attend educational sessions, which should provide information related to the illness, its usual course, the monitoring of emerging consumer behaviors, problem solving and skill building (i.e., communication and behavior management). While these educational programs give you important information about the causes and treatment of mental illness, studies indicate that they are helpful to about two-thirds of those that participate in them. If the educational or self-help groups seem inadequate, we encourage you (especially if you are in the very early stages of coming to terms with the illness) to seek out more specialized services.

Urge

> **"Just because a person has limited capabilities doesn't mean that you expect nothing from him or her"**

Encourage consumers to assume some responsibility for themselves, such as taking care of their personal hygiene, eating enough and going to activities. However, be careful not to put undue demands on them if you sense that they are acutely ill. If they seem capable, start by helping them set one "have to do" goal for each day, such as getting out of bed, getting dressed or taking a shower. Then encourage them to do one "want to do" activity such as watching TV or going for a walk. Success at these tasks increases their self-worth. Compliment them for any accomplishment.

Communicate

Develop an open and honest communication pattern. Let your relative know that you will ask them about your observations, change in moods or behavior changes. Let then know that, while you will try not to be intrusive, you will speak to them of any worries or concerns. Any concerns should be expressed in a caring, supportive way. Let them know when you may want to go along to their next clinical appointment so that you can share your observations and concerns during the visit in their presence. Let them know if you feel that you have to call their physician, counselor, or the police because you think that they are in danger to themselves or that they may harm someone else.

Be Patient

Adapt an accepting attitude. For example, if your relative has Depression or negative symptoms of Schizophrenia, you may have to tolerate a whole day or many days where they do nothing. This inactivity and lack of accomplishment can be upsetting. Practical advice includes helping the consumer make and stick to simple plans, breaking larger tasks into smaller components and giving them credit for whatever is accomplished.

Learn How to Deal with Management Issues

"Despite your best efforts, symptoms may get worse or they may improve"

You have to deal with important management issues that include lack of insight, failure to take medications as prescribed and difficult behaviors. View symptoms and problem behaviors as part of the illness, rather than blaming the consumer for being "lazy" or "uncooperative". While you cannot control the actual symptoms or problem behaviors, you can control your own reactions to these symptoms or problem behaviors

Medications: Taking medication is a very important part of treatment for it reduces symptom intensely and because taking prescribed medications prevents relapse (or worsening). However, evidence indicates that as much as 20-55% of individuals with bipolar disorder have problems staying on their medication schedules. This number is even higher for individuals with schizophrenia. We have dedicated Chapter 14 to this important topic.

Displayed symptoms include hallucinations, delusions, profound depression or mood swings. Recognize and support the need for medical management of these symptoms, particularly when they affect the consumer's ability to work and socialize.

"A delusion is not amenable to reason, so it needs no discussion"

Strange, unpredictable and difficult consumer behaviors include moodiness, unpredictability, irritability, lack of consideration, behaving in a restless way, suspiciousness, embarrassing appearances and strange behavior. Your tolerance for problem behaviors will increase over time. Two explanations for this change include your ability to manage problems more effectively and less problems in consumers who are treatment adherent. Interestingly, some studies show that any behavioral change, even improvements, causes caregiver distress. For example, many caregivers or family members of person with mental illness for many years experience anxiety and confusion because they do not know how to handle the positive changes associated with the new atypical, antipsychotic medications.

Have a Crisis or Emergency Plan

Learn to recognize "early warning signs" of relapse and notify the treating clinician. While symptoms differ from person to person, early signs of relapse include: changes in personal hygiene, changes in sleep patterns, loss of insight, not keeping treatment appointments, adjusting or stopping medication. Your level of distress will increase significantly with severe symptoms, such as violence (threatening or abusive towards anyone else) and parasuicide (consumer speaks about taking his life). When these behaviors occur, they require crisis management and professional support. We recommend that you take any threats of suicide or violence seriously. You should have a plan for whom to contact in emergencies; the plan should include evenings, nights and weekend coverage. The plan should be reviewed with the consumer when he or she is stable so that it is clear that you will follow the plan when you think there is a danger to someone.

Develop Your Own Social Supports

You do not have to be alone in facing the challenge of living with mental illness. *Social supports* are resources, in the form of relationships, on which you can rely. Studies consistently show that social support can improve psychological health because it buffers against stress. **There are many sources of social support and we encourage you to use all of them so you do not burden any one of them:**

- **Family:** Assess the strengths of other family members and discuss with them how they can be of help. Select individuals who are not fearful of the consumer, who can talk with you about current problems and who can help you problem solve difficult situations. Recognize that some family members cannot help you. Recognize that others think they are helping, but only make most situations worse.

- **Friends** provide help and support. Practical help from friends includes listening, providing transportation to appointments, help with shopping and helping with consumer supervision during respite time so that you can have some psychological distance from the consumer.

- **Self-help or support group:** If available, join a local or national self-help or support group. Information on the closest support group to your home should be made available through the treatment center, but these are also available on the national websites listed in the Appendix. These groups are one of the best ways of getting practical advice. Support groups also reduce your social isolation, allow exposure to first-hand experience of others, are informational regarding community resources, and avoid the stigma of a formal therapeutic setting run by professionals.

- **Mental health Professionals:** If possible, be involved in the consumer's treatment plan, especially during a period of hospitalization. Predictably, behaviors (such as violence and suicidal attempts) arise which require crisis management and mental health professionals are the best resource for these. Lastly, mental health professionals provide individual or group therapy services and/or medication treatment when you feel depressed or anxious. Many treatment programs offer supportive interventions or family therapy directed at improving family attitudes and improving family function.

- **Local law enforcement:** Rely on your local police officers and judges to help you, especially if their relative displays disruptive or threatening behaviors. Sometimes, seriously ill persons listen to and cooperate with law officers or judges rather than to their own family members because they think that their relatives have conspired against them or want them to be hospitalized or jailed. When local police officers know the ill person, they can often take them to an emergency room, local shelter or hospital rather than the jail system.

Develop a Range of Coping Skills

"It is not OK for you to be neglected. You have emotional needs and wants too"

Use several types of coping strategies. Strategies include:

- **Initiate or maintain your own activities**: Activities include various types of exercises, creative arts, relaxation, gardening and spending time with good friends.

- **Life management skills**: Life management skills include good nutrition, resting, work or volunteering.

- **Spirituality**: includes praying, meditating, and getting involved in a 12-step program (like Al Anon)

- **Problem solving strategy**: used in situations that the person can manage or handle the problem. Includes the traditional problem solving method of clearly defining the problem, choosing between solutions, taking action and evaluating the effects.

- **Emotion focused:** used in situations that are not in the person's control. Chronic or unchangeable, this type of coping regulates one's emotional response to the situation. Includes cognitive processes such as distancing, avoidance or selective attention.

Learn Healthier Family Coping Skills

"Instead of fear, isolation and shame, there is love, connection and meaning" From: The Binds that Tie and Heal: How Families Cope with Mental Illness

Here is a list of some DOs and DONTs that are posted on the NAMI Maryland web site. This was originally a publication from Families Anonymous Torrance, California.

DO

- **Focus on your own reactions and attitudes.**
- **Allow other people to accept their own responsibility**
- **Manage your anxieties one day at a time.**
- **Invest time reading helpful literature.**
- **Learn to be open and honest.**
- **Involve yourself in support groups**
- **Encourage all attempts to seek help.**

DON'T

- **Nag, argue, lecture or recall past mistakes.**
- **Overprotect or rescue from the consequences of someone else's behavior.**
- **Neglect yourself or be a doormat.**
- **Yearn for perfection.**
- **Manipulate or make idle threats.**
- **Overlook the growth opportunities of a crisis.**
- **Sit home feeling depressed when you could be at a support group meeting, helping yourself and others.**

Positive changes in overall family life are associated with faster recovery times for the consumer. Families do better when they are adaptable, cohesive and have good communication. Also, families who work on developing their strengths, coping skills and resources (finances, social support, health practices) are more resistant to stress and respond better to stressful demands than those families who do not have these qualities.

Know When To Get Professional Help

"Not all families with a problem patient have problems"

Approximately 30-50% of all "normal" American families have problems in some area of their day-to-day function. Therefore, it is not surprising that some families with a severely mentally consumer have some problems. If you are not able to manage the challenge of mental illness in your family, seek professional help. While we have tried to present some standards that define when you should seek help, we encourage you to examine yourselves and your family. You know best when help is needed.

16

Parenting a Mentally Ill Child or Adolescent

A Mother's Letter

To: The Stanley Foundation Bipolar Network

I am writing to tell you how very grateful I am to you and your foundation for giving my daughter, my family and me a lifeboat to solid ground during the worst storm of our lives.

I am the mom of a wonderful 11 1/2 year old daughter who began her difficult days in fourth grade at age 10. She experienced some depression and was put on an antidepressant. It helped the depression but not the focusing and high energy level. She eventually was put on Adderall and that seemed to help some more. Still, she had her struggles over the next year. She is bright, but would "forget" school papers/books for homework. We constantly had to keep after her at home to do everything she was supposed to do. She has a sister who is 15 months younger. Her sister does just great...I was so concerned my daughter would begin to think she was "the bad one" and her sister was "the good one". I had taken her to counselors beginning at age 4...and I had been myself, thinking I just wasn't coping with her. I felt like a horrible mom sometimes...other moms just didn't understand. This kid was physically AND emotionally exhausting me.

Finally, the bottom blew out before Easter of "02. She was so angry and oppositional. Things were worse. She was 11 now. I spoke to my pediatrician again, who had been managing things so far. He suggested possible bipolar and suggested looking at the bpkids.org web site to get some information. He also gave me the phone number of the Stanley Foundation Research Center at University Hospitals of Cleveland. The web site made some sense. I called the research center and did a phone interview. They said she met the criteria for rapid cycling bipolar disorder, and we started our journey.

I have been taking her there every week for 5 months. She entered phase II of the Lithium vs. Depakote trial just about a month ago. We now go every other week for 2 visits, then if she continues to do well...MONTHLY! :) I believe we will make it for phase III, which will last about another year. I will be so relieved to have the help we could need as hormones change more through puberty.

I recently read the article entitled "Young and Bipolar" on Time.com. I sat at my computer reading as tears welled up in my eyes. I looked up to God and thanked Him for you. I thanked Him for your help and for having a great facility near enough to get help. It truly was the worst storm to watch and be in. My daughter is doing so well now. She soon will be on only one medication. We can have great conversations. She wakes up happy. She cooperates in the family. She is all she can be now, thanks to you and your

> foundation. I can not say enough in words to express my deepest gratitude for saving my daughter years of pain and suffering, as well as our family...who love her dearly. God Bless you all and THANK YOU!!!

OVERVIEW

The family is undisputed as the primary caregiving system for most children and adolescents. When children and adolescents become seriously mentally ill, you can suffer considerable burden in coping with the psychiatric illness, especially during its early stages. In this chapter, we report on the findings from a research project within the Department of Psychiatry at Case Western Reserve University, Cleveland Ohio. For this study, we recruited 54 family members who, like the mother in the letter, were motivated enough to seek mental health services at an academic facility and willing to participate in this research project.

The children and adolescents ranged in age from nine to 18, with an average age of 15.4. The children were predominantly white (74%) and male (74%). Their diagnoses were schizophrenia spectrum disorders (N=26), bipolar illness (N=20), major depression (N=5) and psychosis, other (N=3). These were all parents, predominantly mothers (91%), white (74%) and married (70%). Their average age at interview was 42.6 years. For the 35 caregivers who were married, most (83%) indicated that they were happy in their marital relationship and only 4 (11%) indicated unhappiness.

What causes mental illness?

Most parents thought that there was more than one cause for the mental illness in their child. Many of them (82%) cited inherited and/or biological reasons as one possible cause for their child's mental illness. Biological causes included a chemical imbalance, substance abuse or something going wrong during pregnancy or delivery.

How did parents react?

Unlike professionals, parents knew their children many years before the illness. This knowledge affected their current experiences that ranged from shock and disbelief (“how can this be happening to my bright, vibrant and successful child?”) to self-blame (“I always knew this child was different but I didn’t do anything about it!”). About one-half of the parents had symptoms indicative of a level of depression or anxiety that warranted clinical attention.

The parents in our study were moderately burdened when their child or adolescent displayed worry (69%), forgetfulness (67%), misery (63%) and indecisiveness (59%). Although reported in only 25% of the children and adolescents, the most severe levels of parental burden were related to the behaviors of violence (threatening or abusive towards parent or anyone else) and parasuicide (child or adolescent spoke about taking his life).

Regarding social performance, the area of work/study was most distressing to 83% of our parents. Many parents shared concerns about dealing with inflexible school systems and uncaring teachers. In addition, they shared worries about future academic and schooling issues.

The most problematic family problem was affective overinvolvement (or becoming too involved in the care of the child). The next most problematic area was limit setting and defining boundaries between parents and children.

Lastly, our parents identified many needs for service, ranging from needing information about the illness to help with behavior management. In addition, they requested help with management of health care systems and education systems (a need identified earlier among the burden issues) and a need for more peer support groups.

Practical Advice

Clearly, this resource book does not focus on childhood mental illnesses and we encourage you to check our Appendix for a better resource. Also, if your are a parent of a seriously mentally ill child or adolescent, we recommend that you examine your own thoughts about the causes of the mental illness, think about your own current psychological status, and examine your perceptions of burden. Studies indicate that 50-70% of families with a severely mentally ill child report problems (compared with 30-50% of "normal" families).

If you think your responses and needs are "normal" reactions to a very difficult situation, we recommend the following:

- **"listen to your heart"—** You know your child best. If you feel something is not right with your child, pursue it. You may go through several professionals in this field before finding the one your child and/or you "click" with. You may go through many professionals to get the proper diagnosis. It is a journey and can be difficult at times, but we are our child's best advocates. Believe your heart…as you believe your eyes**.**

- **Find and join a support group**. The support group should provide you with information about normal child and adolescent development <u>along with</u> information about the mental illness. Research indicates that support groups are very good for getting most practical advice. Support groups will also reduce your social isolation, allow you to hear first-hand experiences of other parents, get information on community resources, and avoid the stigma of a formal therapeutic setting run by professionals.
- **Form an alliance with the mental health professional(s)**. Learn from them what to expect over the course of your child's disorder. Know your child's "early warning signs" of problems and notify them when you see them. Have a consistent professional that knows

the child and whom you can call. Early signs of problems include: changes in personal hygiene, changes in sleep patterns, changes in appetite, isolation in their room, stopping their medication or not going to school.

- **Plan respite time**. This allows for some psychological distance from the child or adolescent,
- **Have a crisis management and emergency plan.** Severe symptoms of violence (threatening or abusive towards anyone else) and parasuicide (the child or adolescent speaks about taking his/her life) require crisis management and professional help. Take any threats of suicide or violence seriously. Have a plan for whom to contact in emergencies; the plan should include evenings, nights and weekend coverage. Review the plan with your child or adolescent so that it is clear to them that you will follow the plan when you think that they are in danger.

If you are a parent or caregiver who blames the child or adolescent for their illness, who usually feels depressed or anxious, who feels unable to cope, or who experiences severe distress over the child or adolescents behaviors you are in need of more specialized services. These could include individual, group or family therapy. These therapies are aimed at changing your thoughts, feelings or behaviors that are detrimental to your child, adolescent or family's function.

Admission

The admission of your child or adolescent to a psychiatric unit is difficult. While relieved that he or she will get some much-needed help, you are also frightened and anxious about the admission. For some, it is the first time that your child is away overnight; you are generally overwhelmed. Some of you struggle with feelings of guilt, while others expect to be blamed or judged by the mental health professionals. When

Dr. Kathleen Scharer (2000) interviewed and observed nurses and parents during the admission process, she found that most parents, although upset and in crisis at admission, generally were feeling more comfortable within 48 hours of the admission. In fact, many parents were able to relax knowing that their child was in a safe place.

Admission is a critical time to build trust between yourself and staff. From the staff's perspective, the admission is usually a routine process and an important time for assessment, data gathering and information sharing. From your perspective the admission process is an important time to begin to bond with staff. You need to begin to feel that the staff is trustworthy, competent, and nonjudgmental. If the admission process goes well, you bond with the admitting nurse. However, if the process goes poorly, your negative perceptions can last throughout the hospitalization. Some practical advice for you during the admission process includes:

- **Expect to be involved**. Ask for an orientation to the program that can occur at a later date.
- **Work with the care team**. Communicate with them about important issues such as meetings between staff and parents.
- **Learn the routines of the unit**-this information is important so that you can call the unit when it is less hectic and when nursing staff is more available to share information about your child. For example, most mornings are quite busy.
- **Find other parents who can offer support and information** Other parents, especially those who have gone through a hospitalization, are excellent resources for information and guidance.

APPENDIX A

Resources

Alyssa M. Birge, BS

The following is a list and brief description of national agencies and local services that you should access to make it easier for you or a loved one to find the best available support or treatment for mental illness. Where available, we have included web sites for your information.

Alcoholics Anonymous (A.A) www.aa.org

Local: 216-241-7387

"Alcoholics Anonymous is an international fellowship of men and women who have had a drinking problem. It is nonprofessional, self-supporting, multiracial, apolitical, and available almost everywhere. There are no age or education requirements. Membership is open to anyone who wants to do something about his or her drinking problem."

American Psychiatric Association www.psych.org

"The American Psychiatric Association is a medical specialty society recognized world wide. Its 37,000 U.S. and international member physicians work together to ensure humane care and effective treatment for all persons with mental disorder, including mental retardation and substance-related disorders. It is the voice and conscience of modern psychiatry. Its vision is a society that has available, accessible quality psychiatric diagnosis and treatment."

American Psychological Association www.apa.org

"The object of the American Psychological Association shall be to advance psychology as a science and profession and as a means of promoting health and human welfare…"
Please see web site for more information.

Depression and Bipolar Support Alliance (DBSA) www.ndmda.org
Formerly know as the National Depressive and Manic-Depressive Association

"To educate consumers, families, professionals and the public concerning the nature of depressive and manic-depressive illnesses as *treatable* medical diseases; to foster self-help for consumers and families; to eliminate discrimination and stigma; to improve access to care; and to advocate for research toward the elimination of these illnesses."

Mental Health in Ohio www.mh.state.oh.us/

"The primary mission of the Ohio Department of Mental Health is to ensure that quality mental health care is available in communities to all Ohioans, particularly individuals with serious mental illness. Last year, Ohio's community mental health systems provided services to 250,000 people, including more than 75,000 adults who are severely disabled by mental illness and 70,000 children…"

The National Alliance for the Mentally Ill (NAMI)www.nami.org

"The National Alliance for the Mentally Ill (NAMI) is a nonprofit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, major depression, bipolar disorder, obsessive-compulsive disorder, and anxiety disorders. "

(NAMI) National Alliance for the Mentally Ill (Cleveland)
Two local affiliates serve the Cleveland Area.: NAMI Metro and NAMI Cuyahoga County.
Email: namicleveland@msn.com
Website: www.nami-metrocleveland.com

(NAMI) Family to Family Education Classes
12-week peer taught courses designed for family members and other caregivers of individuals with mental illness.

The National Alliance for Research on Schizophrenia and Depression (NARSAD) www.mhsource.com/narsad

"The National Alliance for Research on Schizophrenia and Depression (NARSAD) was incorporated in 1986 through the combined efforts of The National Alliance for the Mentally Ill, The National Mental Health Association, The National Depressive and Manic Depressive Association, and The Schizophrenia Foundation. Recognizing the need for intensive research on the serious psychiatric disorders, concerned family members, citizens' groups' and medical professionals joined together to form NARSAD."

The National Institute of Mental Health (NIMH) www.nimh.nih.gov/

"The National Institute of Mental Health is a division of The National Institute of Health (NIH).
Simply described, the goal of NIH research is to acquire new knowledge to help prevent, detect, diagnose, and treat disease and disability, from the rarest genetic disorder to the common cold. The NIH mission is to uncover new knowledge that will lead to better health for everyone. NIH works toward that mission by: conducting research in its own laboratories; supporting the research of non-Federal scientists in universities, medical schools, hospitals, and research institutions throughout the country and abroad; helping in the training of research investigators; and fostering communication of medical and health sciences information."

The National Mental Health Association (NMHA) www.nmha.org

"The National Mental Health Association (NMHA) is the country's oldest and largest nonprofit organization addressing all aspects of mental health and mental illness. With more than 340 affiliates nationwide, NMHA works to improve the mental health of all Americans, especially the 54 million individuals with mental disorders, through advocacy, education, research and service. "

Plan Of Northeast Ohio, Inc. www.planneohio.org

PLAN is a grassroots organization that was developed by families and staff who wanted something different from the traditional mental health clinic. The result of their efforts is a mental health organization that bears little resemblance to the traditional clinic or private practice model:

- **Mission** To insure that individuals and families impacted by neurobiological illnesses have the opportunities to be active members of a community focused on the total person and the continuity of services needed to achieve enduring growth.
- **Consumers Served**. While the majority of our consumers suffer from major brain diseases (mental illness) such as schizophrenia, major depression and bipolar disorder, we also serve many consumers who have very unique diagnosis and needs and multiple disabilities. The current age range of our consumers is eighteen to sixty-two years of age and they represent every socio-economic stratum.
- **Services** are home based. Very little counseling is done in the office. Therapists visit their consumers regularly at home, at work, or go out for a walk or even for a cup of coffee. Because the therapist comes to the consumer, “no shows” are virtually eliminated (PLAN has a 95% contact rate for appointments met).

eMedguides/Psychiatry www.emedguides.com

This site offers a variety of information on almost every psychiatric topic, ranging from neuropsychiatric information to social and community based psychiatry. It may also help you find a psychiatrist in your area.

The Department of Psychiatry www.uhhs.com/psychiatry
University Hospitals of Cleveland
Case Western Reserve University
Chairman: Pedro Delgado, MD, 216-844-3883
Main Outpatient Number: 216-844-2400 (For all new appointments)
Main Research Number: 216-844-2890 or 216-844-2850

Services within the department

- Treatment for children, adolescents and adults with bipolar disorder, depression and schizophrenia
- The Depression Research Center
- Center of Excellence For Care and Study of Children and Adults with Bipolar Disorder and Alcohol/Drug Abuse
- Electro-Convulsive Therapy program (ECT)
- Cognitive behavioral psychotherapy for depression and anxiety
- Specialized pharmacological treatment for major mental disorders
- Women's mental health
- Biological and psychological effects of emotional trauma

Mental Health Agencies within the Greater Cleveland Community

CHILD and ADOLESCENT

- Achievement Center for Children

- Applewood Centers, Inc.
- Beech Brook
- Bellefaire Jewish Children Bureau
- Berea Children's Home and Family Services
- Catholic Charities of Cuyahoga County
- Center for Families and Children
- Children's Aid Society
- Cleveland Christian Home
- Lutheran Metro Ministries
- Marycrest

- Marymount Hospital Mental Health
- North East Ohio Health Services
- Ohio Youth Advocate Program
- Parmadale Family Services
- Positive Education Program
- St. Vincent Charity Hospital Behavioral Health Services
- UHHS/Laurelwood Hospital

ADULT and GERIATRIC

- The Benjamin Rose Institute
- Bridgeway, Inc.
- Center for Families and Children
- Catholic Charities of Cuyahoga County
- Community Behavioral Health Center
- Cuyahoga County Court Psychiatric Clinic
- Far West Center
- Jewish Family Services Association
- Lutheran Metro Ministries
- Marymount Hospital Mental Health Center
- Mental Health Services, Inc.
- Murtis Taylor Multi-Services Center
- North East Ohio Health Services
- PLAN of North East Ohio (Recovery Resources)
- Psychobiology Clinic of Cleveland, Inc.
- Recovery Resources
- St. Vincent Charity Hospital Behavioral Health Services
- UHHS/Laurelwood
- Visiting Nurses Association

Social and Emotional Support Services

CCCMHB
24-Hour Mental Health Emergency Hotline
216-623-6888

First Help
24-Hour assistance for self-help
216-436-2000

Project One 2 One
Matches volunteers and people with mental illness
216-281-2660

The Phoenix Society
Self-help and Peer Support Group
216-861-4466 or

Warm Line
Peer Support provided 24 hours
440-886-5950

Obsessive/Compulsive (OCD) Support Group
216-442-1739

Manic Depressive/Depressive Association
1-800-826-3632 or 216-321-7811

Schizophrenics Anonymous
440-816-5755

Co-Dependents Anonymous
216-226-9788

Emotions Anonymous
216-752-4333

Alcohol & Drug Resource Hotline
800-252-6465

Cocaine Anonymous
216-523-8701

Narcotics Anonymous
888-438-4673

Drop-In Centers

The following centers provide people a place to interact with peers and mental health providers.

Care Alliance Women's Center
216-781-3414

The Lesbian/Gay Community Service Center
AIDS/HIV Support
216-651-5428

<u>St. Malachi Center</u>
Hot Showers
216-771-3036

<u>The Spot</u>
Homeless Adults with Mental Illness
216-623-2134

<u>West Side Catholic Center</u>
216-631-4741

<u>YWCA New Day</u>
For Women Only
216-781-3414

APPENDIX B

Cited References

Anthony W, Cohen m and Farkas M. Psychiatric Rehabilitation. Center for Psychiatric Rehabilitation.

Aquila, R., Santos, G. Malamud, T. J., & McCrory, D. (1999). The rehabilitation alliance in practice: The clubhouse connection. *Psychiatric Rehabilitation Journal*, 23, 1, 19-23.

Beard, J.H., Propst, R. N., & Malamud, T.J. (1982). The Fountain House model of psychiatric rehabilitation. *Psychosocial Rehabilitation Journal*, 5, 1, 47-53.

Beard, J. H., Malamud, T. J., Rossman, E. (1978). Psychiatric rehabilitation and long-term rehospitalization rates: the findings of two research studies. *Schizophrenia Bulletin, Vol. 4,* 622-635.

Bradshaw W. Integrating cognitive-behavioral psychotherapy for persons with schizophrenia into a psychiatric rehabilitation program: results of a three-year trial. Community Mental Health Journal 2000 Oct: 36 (5):491-500.

Budd RJ and Hughes ICT. What do the carers of people with schizophrenia find helpful and unhelpful about psycho-education? Clinical Psychology and Psychotherapy, vol. 4 (20, 118-124 (1997).

Chamberlin, J., Rogers, E.S., & Ellison, M.L. (1996). Self-help programs: A description of their characteristics and their members. *Psychiatric Rehabilitation Journal*, 19 (3), 33-42.

Colom F, Vieta E. Treatment adherence in bipolar consumers. Clinical approaches in bipolar disorders 2002; 1: 49-56

Colom R, Vieta E, Martinez-Aran A, Reinares M, Benabarre A, Gasto C. Clinical factors associated to treatment non-adherence in euthymic bipolar consumers. J Clin Psychiatry 2000; 61: 549-554

Craig TJ, Fennig S, Tannenberg-Karant M., Bromet EJ. Rapid versus delayed readmission in first-admission psychosis: quality indicators for managed care? Ann Clin Psychiatry 2000 Dec; 12 (4); 233-8.

Cramer JA, Rosenheck R. Enhancing medication adherence for people with serious mental illness. J Nerv Ment Dis 1999; 187(1): 53-5

Dincin, J. (1975). Psychiatric rehabilitation. *Schizophrenia Bulletin*, 13, 131-147.

Epstein NB, Baldwin LM and Bishop DS. (1983) The McMaster Family Assessment Device Journal of marital and Family Therapy 9: 171-180.

Flannery, M., & Glickman, M. (1996). Fountain House: Portraits of lives reclaimed from mental illness. Center City, MN: Hazelden.

Frese, F., Stanley, J., Kress, K., & Vogel-Scibilia, S. (2001). Integrating evidence-based practices and the Recovery Model. *Psychiatric Services*, 52 (11), 1462-1469.

Gravity H. The binds that tie-and heal: How families cope with mental illness. *Psychology Today* March, 2001.

Goodwin, F, and Jamison, K. Manic-Depressive Illness from Oxford Press

Hall L & Beinecke R. (1998) Consumer and family views of managed care. New Directions for Mental Health Services, 78,77-85.

Hatfield AB, Bearon JS and Coursey RD. Family members' ratings of the use and value of mental health services: results of a national NAMI survey. Psychiatric services, 1996 August :47 (8): 825-31.

Horesh N and Fennig S. Perception of spouses and relationships: a matched control study of consumers with severe affective disorders in remission and their spouses. J. Nerv. Ment. Dis. 2000 July; 188 (7):463-6.

Horovitz-Lennon M, Norman ST, Gaccione P and Frank RG. Partial Versus Full Hospitalization for Adults in Psychiatric Distress: A Systematic Review of the Published Literature (1957-1997). American journal of Psychiatry may 2001 158:676-685.

Jackson, R. (2001). The clubhouse model: empowering applications of theory to generalist practice. Toronto, Canada: Brooks/Cole- Thomson Learning.

Jackson, R. (1992). How work works. *Psychosocial Rehabilitation Journal*, 16 (2), 49-54.

Jamison KR, Gerner RH, Goodwin FK. Consumer and physician attitudes toward lithium. Arch Gen Psychiatry 1979; 36: 866-869

Kahn David A , Ross Ruth, Printz David J and Sacks Gary S. Treatment of Bipolar Disorder: A Guide for Consumers and Families. A Postgraduate Medicine Special Report, April, 2000.

Karp D A. The burden of Sympathy: How Families Cope with Mental Illness Oxford University Press, 2001.

Keck P, McElroy B, Strakowski S et al. Factors associated with pharmacologic non-adherence in consumers with mania. J Clin Psychiatry 1996;57:292-297.

Lingam R, Scott j. Treatment non-adherence in affective disorder. Acta Psychiatr Scand 2002; 105(3): 164-72

Maarbjerg K, Aagaard J, Vestegaard P. Adherence to lithium prophylaxis, I: Clinical predictors and consumer's reasons for nonadherence. Pharmacopsychiatry 1988: 21: 121-125

Macias, C., DeCarlo, L.T., Wang, Q., Frey, J. & Barreira, P. (2001). Work interest as a predictor of competitive employment: Policy implications for psychiatric rehabilitation. *Administration and Policy in Mental Health*, 28, 4, 279-297.

Malamud, T. J. (1985). Community adjustment: evaluation of the Clubhouse model for psychiatric rehabilitation. *Rehabilitation Brief,* Vol. 9, No. 2.

Marsh D.T. A Family-Focused Approach to Serious Mental Illness

Miklowitz DJ. Longitudinal outcome and medication non-adherence among manic consumers with and without mood-incongruent psychotic features. J Nerv Ment Dis 1992: 180: 703-711

Miller J M. In Harm's Way: The Imminent Financial Threat to Mental Health care services in Medicaid Programs. NAMI Advocate, Winter, 2003: 19-21.

Muller-Oerlinghausen B, Muser-Causemann B, Volk J. Suicides and parasuicides in a high risk consumer group on and off lithium long-term treatment J affect Disord 1992; 25: 261-269

Ohio Department of Mental Health. (1999). “Mental Health and Recovery Process and Best Practices Model”.

Olson D, McCubbin HI, Barnes H, Larsen AS, Muxen MJ and Wilson MA. Families-What Makes Them Work Sage Publications, Inc. 1989.

Patterson W, Dohn HH, Bird J, and Patterson G. Evaluation of suicidal consumers: The SAD PERSONS scale. Psychosomatics, 1983, Vol. 24, No.4, 343-349.

Perlick D, Clarkin JF, Sirey J, Rau P, Greenfield S, Struening E, Rosenheck R. Burden experienced by care-givers of persons with bipolar affective disorder. *Br J Psychiatry*, 1999, July;175:56-62.

Phelan JC, Bromet EJ and Link BG. Psychiatric Illness and family stigma. Schizophrenia Bulletin 1998; 24 (1):115-26.

Pratt, C.W., Gill, K.J., Barrett, N.M, Roberts, M.M. (1999). Psychiatric Rehabilitation. San Diego, California: Academic Press.

Scharer K. Admission: A crucial point in relationship building between parents and staff in child psychiatric units. Issues in Mental Health Nursing. 2000 21:723-744.

Scott J. Predicting medication non-adherence in severe affective disorders . Acta Neuropsychiatrica 2000; 12: 128-130, 2000

Scott J, Pope M. Self-reported adherence to treatment with mood stabilizers, plasma levels, and psychiatric hospitalization. Am J Psychiatry 2002: 159: 11,1927-1929

Secunda V. When Madness Comes Home. New York: Hyperion, 1997.

Shyovitz M. A family member’s legal experience with an insurer’s refusal to recertify inpatient mental health treatment. J Clin Psychiatry 2001;62 suppl 25:44-50.

Snyder CR (ed) Coping: The Psychology of What Works

Struening EL, Perlick DA, Link BG, Hellman F, Herman D, Sirey JA. Stigma as a barrier to recovery: The extent to which caregivers believe most people devalue consumers and their families. Psychiatric Services 2001 Dec;52 (12): 1633-8.

Suppes T, Baldessarini RJ, Faeda GL, Tohen M. Risk of recurrence following discontinuation of lithium treatment in bipolar disorder. Arch Gen Psychiatry 1991: 48: 1082-1088

Surgeon General's Report on Mental Health, 1999.

Tennakoon l, Fannon d, Doku V, O'Ceallaigh S, Soni W, Santamaria M, Kulpers E, Sharma T. Experience of caregiving: relatives of people experiencing a first-episode of psychosis. *Br. J Psychiatry,* 2000, Dec;177:529-33.

Terkelson, K. The Evolution of Family Responses to Mental Illness through Time. *In Families of the Mentally Ill: Coping and Adaptation.* Edited by A.B. Hatfield and H.P. Lefley, New York: The Guilford Press 1987.

Terkelson, K. The Meaning of Mental Illness to the Family. *In Families of the Mentally Ill: Coping and Adaptation.* Edited by A.B. Hatfield and H.P. Lefley, New York: The Guilford Press 1987.

Tsang HW. Rehab rounds; Social skills training to help mentally ill persons find and keep a job. Psychiatric Services 2001 Jul;52 (7): 891-4. Boston, Massachusetts, 1990.

Vorspan, R. (1992). Why Work Works. *Psychosocial Rehabilitation Journal*, 16 (2), 49-54.

Weiss RD, Greenfield SF, Najavits LM, Soto JA, Wyner D, Tohen M, et al. Medication adherence among consumers with bipolar disorder and substance use disorder. J Clin Psychiatry 1998: 59: 172-174.

Zametkin AJ, Alter MR and Yemini T. Suicide in Teenagers: Assessment, Management, and Prevention. JAMA December, 2001, Vol. 280, No. 24, 120-125.

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