A Balanced Life

9 Strategies for Coping with the Mental Health Problems of a Loved One

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To our support group, which meets on the first and third Thursday of every month:

You experienced and refined these strategies before they were a book. Thank you for your stories of hope, and for your inspiration, courage, and wisdom.

Contents

Acknowledgments

This book reflects both the painful and the joyful experiences of many people who are the families and friends of a loved one with mental health problems. Through listening to their stories, many of which mirror my own life, I was encouraged to write this book. In particular, I am grateful to the members of the Karla Smith Foundation's "Hope for a Balanced Life" support group—a group for the family and friends of people with mental illness. Some of them contributed stories of hope for this book, and I appreciate their honesty in sharing their experiences and their courage in seeking solutions to difficult life situations.

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Finally, and sadly, I am grateful to my daughter, Karla. I certainly wish it were otherwise, but her struggle with bipolar disorder and her suicide introduced me, on a personal level, to the world of mental illness. This book honors her memory, as she would want it.

Preface

This book flows from my family's own experience. Our realization that this book was needed, and the eventual form it took, were shaped by our story. That story is still unfolding, but here I will share its beginnings with you.

My wife, Fran, and I had been married two years when our twins, Kevin and Karla, were born. Throughout their childhood and adolescence, we were a normal, happy, middle-class family dealing with the predictable issues of family life and parenting.

Then, very suddenly in January 1996, when Karla was nineteen and beginning the second semester of her sophomore year in college, she fell into her first major depression. She abandoned school, came home, crawled beneath the covers of her bed, and barely left her room.

We sought help from a psychiatrist and a counselor. With medication and counseling, Karla eventually came out of the depression, but only after her first suicide attempt. In the summer and fall of 1998, she experienced her first major manic episode. After several torturous and bizarre months, she ended up in

a mental health treatment center in Las Vegas, New Mexico, where she was diagnosed with bipolar disorder.

There were more emotional and behavioral ups and downs, but eventually she stabilized enough to go back to college and earn a 4.0 GPA. She was about to graduate when, in the summer of 2002, she slipped into another devastating, four-month manic phase—which then cycled into an even more destructive depression in November and December.

On New Year's Eve, after Karla lapsed into a suicidal, catatonic state, Fran took her to a behavioral health care center in Tulsa, Oklahoma, where she was admitted. On January 10, the center released her against our wishes. Three days later, she found a hidden .22-caliber rifle, held it to her chest, pulled the trigger, and died instantly as the bullet ripped through her aorta. She was twenty-six, beautiful, intelligent, and charming, with a promising future. And she was dead.

Our grief remains profound. In the aftermath of her suicide and in memory of her, Fran, Kevin, and I did two specific things. First, we wrote a book, *The Tattered Tapestry,* describing our family's experience with Karla's bipolar illness, her suicide, and our own continuing grief.[1] Second, we formed the Karla Smith Foundation, whose mission is to "provide hope for a balanced life to family and friends of anyone with a mental illness or who lost a loved one to suicide." Its Web site is at www.karlasmithfoundation.org. In service of this mission, the Foundation teaches and promotes nine strategies for coping with the mental disorder of a loved one. These strategies emerged from our own experience of Karla's bipolar illness, the shared stories of others in similar situations, and our research through books, conferences, videos, and the Internet.

This book, *A Balanced Life,* is the result of our experience and research. Its nine chapters reflect the nine strategies. Each includes a commentary on that strategy, real-life stories of hope from those who have used it, and a series of questions for personal reflection and group discussion. Together, these strategies form the guiding material of the Karla Smith Foundation's sup-

port groups for the family and friends of a loved one with mental health problems.

What kinds of problems? In general, this book assumes that the person in question has a moderate to severe psychiatric disorder that is persistent or chronic. These people usually require ongoing long-term treatment and support from a network of people, including professionals, family and friends, and often the community. People with nonsevere disorders—such as milder forms of depression, anxiety, attention deficit disorder, and so on—usually need less intensive personal support; they can often lead independent, normal lives with medication, therapy, or both. Throughout this book, when we refer to mental illness, mental or psychiatric disorders, or mental health problems, we are talking about severe and chronic illnesses. And, although some mental disorders are apparent from birth, many of them emerge later, either gradually or suddenly, in childhood, adolescence, or adulthood. These later-onset disorders are the type primarily discussed in this book.

During the seven years my family struggled to cope with Karla's bipolar disorder, we received very little guidance. We had no coordinated response to her and no consistent advice on how to help her; no one attempted to understand or clarify our frustration, concern, and fear; we had no manual that suggested ways to cope with her mental problems. We did what we thought was the best for Karla, but we did it without confidence, and we regularly second-guessed ourselves.

We wish we had had these nine strategies to guide us while we tried to manage our responses to Karla and her disorder. We know that for every person with mental health problems, there are family members and friends who struggle as we did. We offer this book as a help to them, and we believe that living these strategies will bring balance, hope, and peace in troubled times.

Introduction

Mental illnesses are shockingly common; they affect almost every American family. It can happen to a child, a brother, a grandparent, or a co-worker. It can happen to someone from any background. It can occur at any stage of life, from childhood to old age. No community is unaffected by mental illnesses; no school or workplace is untouched.

. . . . . .

In any given year, about 5% to 7% of adults have a serious mental illness. . . . A similar percentage of children—about 5% to 9%—have a serious emotional disturbance. These figures mean that millions of adults and children are disabled by mental illnesses every year.

These startling statistics were revealed in a 2003 report, *Achieving the Promise: Transforming Mental Health Care in America*,

by the President's New Freedom Commission on Mental Health.[2] And each of these millions of people has a network of family and friends. If we assume at least four family members or close friends for each, then the number of people in the United States personally affected by mental illness is over 100 million.

Staggering as that number is, mental illness is experienced one person, one family, one friend at a time. While many symptoms are somewhat similar among people with the same general disorder, the individual stories of pain, confusion, frustration, and stigma are agonizingly personal.

Some people cope with their mental health problems quite well. They lead relatively balanced, productive, long lives and die of natural causes unrelated to their disorder. Other people suffer greatly, unable to control the extremes of their illness. They may limp from one major episode to another, they may live in a medicated haze, or they may create their own internal world severed from what most people consider reality.

Sometimes the mental illness ends in suicide. While suicides may involve a variety of factors—sociological, economic, and drug-related, among them—mental illness plays a part in many of them. The World Health Organization found in 2001 that suicide causes more deaths worldwide every year than homicide or war.[3]

But mental disorders can be managed, at least to some extent. Every situation is unique, but this is a fact for all people with a mental disorder: they can't manage the illness without some help. Left unchecked (which, in most cases, also means unmedicated), the illness will dominate a personality. The deterioration may be slow or rapid, but an untreated mental, behavioral, or emotional disorder will likely lead to increasingly pronounced erratic behavior—or at the very least, the condition will not improve. To control the illness, some type of treatment is necessary.

The nine strategies discussed here offer practical, humane ways to cope. While this book is written for the family and friends of a loved one with severe and persistent mental health problems, it could also directly benefit the person with the disorder, too. Ideally, that person might also read and discuss this book with

friends and family to better understand their point of view—and to offer partnership with the strategies, if possible.

Balance

For people with a mental disorder and those who love them, the ultimate goal is recovery, which means balance. Anyone can strive for greater balance in life: that is a worthy goal. But most people without a mental illness already strike an acceptable level of emotional and behavioral balance somewhat automatically. Their body chemistry is relatively stable, and their emotional highs and lows stay within an expected range. Only at times of particular stress do these people feel a special need to rebalance their lives emotionally, mentally, spiritually, and behaviorally. And they regain that balance fairly easily, with medication, therapy, or simply with improved circumstances and time. For the most part, setting a goal to achieve a balanced life is not something they're especially motivated to do—there's no significant imbalance in their lives to recover from.

But for people with mental illness and those who love them, balance is not automatic. It must be achieved through conscious effort and planning, using effective strategies. And even when it is attained, balance does not mean the illness is cured. It means that it is contained, that the dangerous extremes of the disorder are usually in check. It means that the person can live a relatively peaceful and productive life with relationships that are stable and enriching, that the person can recover from a relapse with some confidence, and that the person's loved ones can enjoy a similar life.

With emotional, mental, spiritual, and behavioral balance, many people with mental disorders can experience life within the "normal" range of emotions, thoughts, and actions. They can manage in mainstream society without needing long-term institutionalization or withdrawal from life's daily challenges.

And these nine strategies can help strike and maintain that balance. Some people with severe brain damage or mental disability may not be able to comprehend the strategies, and they may

need more specialized care. But for the millions who suffer from mood disorders, such as major depressive or bipolar disorders, these nine strategies, when reworded to apply directly to them, can provide a path to balance, productivity, healthy relationships, and peace. The same goes for many who suffer from schizophrenia, personality disorders, and anxiety or other disorders.

Mental disorders vary widely from person to person, and so do the solutions for managing them. Some of the strategies in this book may be most effective with particular types of illness, but much depends on the individual, too. The experience of a mental illness is unique to each person. Therefore, the path to a balanced life is different for each person traveling it. On the other hand, there are many common symptoms and experiences; indeed, this commonality makes it possible to formulate these nine strategies. The strategies can always be adapted to the particular situation at hand, as long as this is done within the strategies' general structure and spirit. Actively practicing all nine of them can greatly aid in achieving a balanced life for all concerned.

The Nine Strategies

Family and friends are often confused, angry, and frustrated by the behavior of their loved one. Even if counseling and treatment are underway, and family members have learned some basics about the illness, they may have no idea how to apply that knowledge: What can they do? How can they relate to the person? What should they be alert for? And how do they manage their own life balance in the process?

The nine strategies offer guidance on how to support the loved one and what to expect from him or her. Living with and responding to a person with a mental disorder often leads to emotional chaos. We may need to learn some new approaches. The relationship skills we've developed in "normal" settings over the course of our lives may not work as expected when we are relating in the chaotic world of mental illness. The rules are constantly changing, the dynamics of the relationship are volatile,

and expectations are unanchored in everyday reality or common sense. Understandably, frustration is the result.

These strategies can bring some order to the chaos. They provide a framework for responding to the person with mental illness. They specify ways to provide advice and encouragement. They clarify expectations. They offer a systematic response to the question *What can I do?* And they are reliable,

The Nine Strategies

1. Help our loved one find and continue to take the medication needed for a balanced life.
2. Urge our loved one to maintain a supportive relationship with a therapist, counselor, or sponsor.
3. Learn as much as we can about the mental disorder of our loved one.
4. Assist our loved one in developing a healthy self-esteem, since it is critical for a balanced emotional life.
5. Accept mental illness as a fact of life for our loved one, even though this mental illness does not encompass all of life.
6. Take care of ourselves by proper exercise, sleep, diet, relationships, and by monitoring our feelings.
7. Become a supportive network of family and/or friends who know about the mental illness and who commit to acting in the best interest of our loved one as far as we are able.
8. Identify the early warning signs that precede a more difficult phase of the mental illness, and help our loved one when these signs emerge.
9. Acknowledge our dependence on a Higher Power and seek guidance from that Higher Power in whatever way that is comfortable to us.

since they are well grounded in experience and research; they are tested and proven.

As you apply these strategies on an ongoing basis, feel free to develop additional ones as needed. You may find that one of them has a particular aspect that warrants more attention. You might "spin off" that aspect into a tenth or eleventh strategy and focus even more consciously on it.

Whether you add to the list or not, consider these nine to be essential. Each one plays a specific role in helping manage the disorder, and to ignore any one of them could undermine all of them, maybe even dangerously. They are all about equal in importance, with strategy 1—medication—the absolutely pivotal one for most people. A person may be able to fudge slightly on the other strategies from time to time and avoid the extreme consequences of the illness. But not to stick with a properly prescribed and monitored medication plan is a sure path to disaster. With these strategies, by far the best approach is to accept and continually apply all nine. This commitment offers the greatest opportunity for ongoing emotionally balanced living.

A Long-Term Approach

Keep in mind the difference between a strategy and a tactic. A strategy is a plan of action designed to achieve a future outcome, usually for the long term. In the context of achieving balance with mental illness, these strategies anticipate significant change, and once implemented, they offer an ongoing improved way of thinking, feeling, and acting. A tactic, on the other hand, is a short-term action that produces a desired outcome. Strategies look to a future, more enduring result.

Coping

What do we mean by the term "coping"? We mean that we and our loved one are managing the impact of the illness well enough that we can live a reasonably peaceful life, and that the conse-

quences of the illness do not interfere excessively with our daily living. Everyone has achieved an acceptable ongoing pattern of living. Everyone makes the necessary adjustments to relieve the burdens that living with mental illness can impose.

Coping does not mean the illness is cured. For the person with the disorder, coping means that it is controlled well enough to allow for extended times of reasonably peaceful living. For family and friends, coping means that even during ongoing difficult episodes or perhaps even disruptive psychotic behavior, they can remain relatively calm, helpful, concerned, and loving—but detached enough to continue their own lives. If there is a relapse into an extreme episode, everyone can return after intervention and treatment to an acceptable living pattern once again.

Coping is not a passive attitude. It is not something that happens *to* people; it requires consistent positive action. The strategies work for us only if we "work" them—if we use them actively. Working the nine strategies is anything but passive. We're not just memorizing them. We're applying them regularly. Reflecting, discussing, seeking implications, gaining insights from other people and resources, and discovering how the strategies impact us differently as the years go by—all these activities are implied in the term "coping." It takes work to cope. The nine strategies are guides to that work.

Mental Illness

Mental disorders take many forms. *The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV),* published by the American Psychiatric Association, identifies hundreds of them. General classes of mental disorders include depressive disorders, bipolar disorders, anxiety disorders, eating disorders, personality disorders, and schizophrenia, among others. Each of these classes is divided into specific disorders. For example, according to the *DSM-IV,* the anxiety disorders class is divided into the following specific disorders: panic

disorder without agoraphobia, panic disorder with agoraphobia, agoraphobia without history of panic disorder, specific phobia, social phobia, obsessive-compulsive disorder, posttraumatic stress disorder, acute stress disorder, generalized anxiety disorder, anxiety disorder due to a general medical condition, substance-induced anxiety disorder, and anxiety disorder not otherwise specified. (For more information on mental disorders, see appendix A.)

How many individuals with the various disorders described in the *DSM-IV* will respond to these nine strategies? It's hard to say. The first step is comprehension. To use the strategies, a person needs to understand their general meaning. If the mental illness prevents that, the strategies will be ineffective for that person. The second step is application. When someone does understand the core concepts, it becomes a matter of putting them to use—of living them. With those two steps, success is possible, and many disorders can be managed. The coping skills fostered by these nine strategies are not tailored to a particular mental illness; they are flexible enough to fit many situations.

What if the person with the disorder cannot or will not apply the strategies? The strategies can still have value for other people involved. Loved ones who follow the strategies can achieve some peace in their own lives, even as they relate to the person whose disorder is unmanaged. Coping with their loved one's frustration, anger, helplessness, and fear while showing patience and love is often a tremendous challenge for family members and friends. The nine strategies provide a road map to love without enabling, care without codependence, independence without abandonment, serenity without surrender, and order without controlling.

Try them and see if these strategies apply to your situation. They probably do—because they are flexible. They don't prescribe an exact solution; they help you organize your response to the disorder, and they provide a checklist of the major keys to coping with mental illness. Make a serious effort to use these

strategies—and then decide whether they apply. Give them a good chance to work.

Group support is a big plus for families and friends, too. Find a group of people who are in situations like yours—ideally people who are also using or willing to use the nine strategies. Sharing your insights and experiences can be invaluable.

A mental disorder is not an automatic condemnation to a life of misery—either for the person diagnosed or for the family and friends. There is hope and opportunity for people with mental illness and those who love them. They can all live a balanced life, and these nine strategies will help.

Dual Diagnosis with Substance Abuse

In many cases, people with mental health problems also abuse or become addicted to alcohol or other drugs. This co-occurring disorder can complicate both diagnosis and treatment—of the mental illness as well as the substance use problem. (See appendix B for a more thorough discussion of substance abuse and dependence and how to respond.) The substance use may begin as a way to self-medicate the mental illness, an attempt to dull the emotional pain. However, for 8 to 10 percent of the general population, use can lead to abuse or dependence. In these cases, both the mental disorder and the substance use problem need to be addressed, preferably simultaneously in an integrated treatment program. And this "dual diagnosis" can mean even more confusion and frustration for everyone involved. How do we deal with both mental illness and addiction?

A dual approach can help us, too: we can get support for coping with both aspects of the problem. The nine strategies outlined in this book are consistent with the principles and practices of Al-Anon and Alateen, the Twelve Step programs that have been extremely helpful for the families and friends of alcoholics and addicts. Consider joining an Al-Anon support group as well as a mental health support group, as described above.

For the person with the dual diagnosis, Twelve Step groups such as Alcoholics Anonymous (AA), Narcotics Anonymous (NA), and Cocaine Anonymous (CA) offer invaluable support for recovery. These groups hold regular meetings—generally at least weekly, often daily. Many cities have multiple groups that meet in various locations. Some communities also have dual disorder support groups, such as Dual Recovery Anonymous (DRA).

Helping a Loved One

With these nine strategies, we are helping both ourselves and our loved one. Six of them call for us to take action that will directly improve our own coping abilities. And three of them—strategies 1, 2, and 4—speak of the need to *help, urge,* or *assist* the loved one. What does it mean to help, urge, or assist a person with a mental illness? It means to take an active role or even a proactive role in the care of the person, not waiting for him or her to ask for help. It means offering support emotionally, socially, spiritually, and intellectually. It means to advocate for your loved one when he or she is unable or unwilling to act in his or her own best interest.

And what about the term "loved one"? In some situations, family and friends don't always feel much love for the person with the diagnosis. At times, our frustration can so affect our feelings that it's hard to find the love anymore. Anger, disappointment, and powerlessness can override more positive feelings. These feelings of love and loss of love can come and go, and that is natural. So, for our purposes in this book, a "loved one" is anyone we have some responsibility for or care about personally. It may be a close family member or a friend. It can be a child, adolescent, or adult. It usually is someone we have known or lived with for a long time. A loved one is more than an acquaintance, a casual friend, or a co-worker sharing a job-based relationship. There is some level of commitment and responsibility for the person. We know that we will remain involved with

the person even if, in our frustration, we sometimes feel like we want out of the situation.

We may not feel the love all the time. But as we learn more about the illness and work these nine strategies, we may find that we feel it more consistently.

STORIES OF Hope

What do these strategies look like in action? Each chapter in this book closes with several "stories of hope" based on actual life experiences. They tell about real people who have been through what we're going through—stories that may be hopeful, inspiring, tragic, or perhaps all of the above. They are all true in that they reflect the reality of loving a person with mental health problems. To protect anonymity, however, some of the names and details have been changed, and some are composite stories of people with similar experiences.

QUESTIONS FOR GROUP DISCUSSION OR PERSONAL REFLECTION

1. How much have you learned about mental illness in general?
2. How much do you know about the kinds of treatment and help available for a person with mental health problems? For the person's family and friends?
3. What does it mean to you to "lead a balanced life"?
4. How has living with a loved one with mental health problems created imbalance in your life?
5. Does your loved one have a dual diagnosis? If so, describe the relationship between the mental illness and the addiction.

6. Do you agree with the approach to "coping" described in this chapter? Do you believe that this level of coping is possible for you? Write down in what ways it is or isn't possible in your situation.
7. Outline the history of your loved one's mental health problems and the impact those problems have had on your family or friendship.

CHAPTER ONE Medication

STRATEGY *1* *Help our loved one find and continue to take the medication needed for a balanced life.*

It sounds simple enough: take your medication. If you need medication for a balanced life, what could be more obvious? You get a prescription, then follow through and take it as indicated. It usually amounts to a pill or two, once or twice a day. People do it for all kinds of ailments, diseases, or pains. Many healthy people take pills to prevent illness, boost vitamin levels, reduce weight, strengthen bones, or replace hormones. Taking needed medications and supplements has become an everyday habit in our society, as common and natural as eating balanced meals.

Why, then, is taking their medication such an issue for so many people with mental health disorders?

It is, in fact, a serious problem. Getting the right prescription is the first hurdle. Thousands of people with mental illnesses

don't have easy access to a professional who can prescribe medication; others are misdiagnosed and don't get the proper drug or the proper dose. But even with a correct diagnosis and the right prescription drug, some people may refuse to take it, forget to take it, stop taking it after starting it, fail to get refills in time, or adjust their own dosage without the guidance of their counselor or doctor. The consequences of any of these common behaviors is very likely to be a relapse into an unbalanced emotional state.

An outsider might judge these behaviors as foolish and irresponsible. The reality is more complicated, as we will see in our discussion of strategy 1.

The great majority of people with a severe, persistent mental disorder do need medication, usually in conjunction with counseling. Some may need medication initially until they are stabilized and able to take advantage of counseling—at which time they can reduce or discontinue their medication and resume it only if they have a relapse (a sequence of steps that must be supervised by a mental health professional). And in some less severe cases, balance may be achieved with counseling alone. But for most, medication is a key, ongoing necessity. Let's look at this crucial factor in more detail.

Finding the Medication

The challenges begin with the onset of the mental illness. While an early, quick, and accurate diagnosis of the disorder is obviously the best-case scenario, more often than not, signs of a mental health problem emerge slowly and with many confusing signals. Months, even years, may pass before the behavior reflecting a mental disorder leads to a diagnosis. In the meantime, the sufferer tries to understand and cope with thoughts, feelings, and behavior that stretch and then exceed the limits of normal. Family, friends, and co-workers, too, witness and experience this confusing struggle themselves. At this early stage, pinpointing a diagnosis—let alone the proper medication—is nearly impos-

sible because the presenting symptoms are so complex and hard for everyone to interpret. Even doctors and other professionals may have trouble determining the exact nature of the disorder immediately. As a result, many people do not receive the medication they need as soon as they need it.

The complications can continue even after an accurate diagnosis is made. Choosing the right medication is not an exact science. Often, there are many drugs that are designed to control the symptoms of a specific disorder. Which one fits a given patient best? What factors lead a psychiatrist to prescribe a particular drug or combination of drugs for a patient? What dosage is needed? Many variables enter into those decisions: the intensity of the symptoms; the medications' side effects; the patient's personality, general health, and lifestyle; insurance plans and ability to pay; and so on.

Timing is another variable. Some drugs take weeks or months to make a noticeable difference—time that may be filled with discomfort and uncertainty. And even when an effective drug or combination of drugs is identified and taken consistently, there is no guarantee that it will remain effective forever. Eventually the patient's body chemistry may change, and the medication may lose its impact.

The side effects may create other physical or emotional problems as well. In response, the prescriber may adjust the dosage, switch to a new medication, or add a drug to counter the side effects. The jigsaw puzzle of factors may become more complex over time. It may seem that with each adjustment the cycle of cause and effect begins again, and more adjustments inevitably follow.

Finding the right medication is not simple, and the search seldom ends with the first choice. It may be a long process.

Finding Professional Help

Who will prescribe the medication? A psychiatrist or other mental health professional will need to choose it, prescribe it, and

monitor it over time, preferably in an ongoing relationship with the client. Finding this person may also be difficult. How do we begin?

Everywhere in the United States, psychiatrists and other medical doctors can make a diagnosis and prescribe drugs. But beyond that, the professional credentials required to prescribe medications may vary from state to state. In some states, nurse practitioners can, too, and in a few states, Ph.D. psychologists can. Check with your counselor, social worker, or physician to find out your state's requirements.

Most counselors who can't prescribe meds are associated with a doctor or other professional who can, and they refer their clients to him or her for that purpose. Unfortunately, these specialists often have full schedules, and newly diagnosed people can wind up on waiting lists. If an episode reaches the level of possible suicide or other threat of harm, the person may be admitted to a hospital emergency room or treatment center. While in treatment, a person diagnosed with mental health problems will receive medication.

After the person leaves the facility, continuing access to medication becomes more problematic. For people with insurance, maintaining contact with the facility's doctor for meds is usually easier. For people without insurance, a variety of state-sponsored programs offer medication—but there is often a high turnover rate among the doctors who prescribe the meds. Doctor-patient relationships are often impersonal and short-term.

We live in a mobile society. If the patient tends to move often—as many college students and young adults do—finding the right professional help becomes even more complicated. And people with severe mental illnesses tend to lead more transient lives than the general population; some are estranged from their families. With each change of address comes the need to find a new person to prescribe the proper medication. And in this scenario, medical records often don't follow the patient in time for the new professional to study the medication history and weigh those factors in the balance. Besides, different profession-

als prefer different medications; their access to free samples of drugs may also differ. The counselor-patient relationship suffers, as does consistency in follow-through. Will the patient take the right meds in the right doses—or even take them at all?

How can family and friends help? They can

- help their loved one stabilize their living arrangements, if necessary
- find a reputable doctor or other mental health professional who can diagnose mental illnesses and prescribe meds
- help their loved one understand the dosage and side effects, and help devise a reminder system for taking the meds on schedule
- help their loved one handle any changes in meds and dosages over time. These adjustments are almost inevitable, and they can be frustrating, so emotional and practical support are helpful. The prescriber should also be kept up to date about the patient's response to the treatment.

What if the person denies having a mental disorder? Take the initiative and act independently: find a professional, discuss the problem, and together create a plan on how to approach the person's need for medication and other treatment. Meanwhile, you can join a support group for your own needs. Together with other people, you can seek ways to live with and love the person with mental health problems who won't accept help.

Staying on the Medication

The commitment to keep taking medication is as necessary as the initial commitment to begin taking it. Unfortunately, many people do quit their meds. Why?

Once stabilized, some people are lulled into thinking that they are now cured and no longer need to take their pills. As attractive as that idea is, it doesn't happen that way in practice. The medication is a major ongoing factor in their stabilization, and without it, the newfound balance is thrown off again.

Side effects are another reason. People usually experience some side effects, which vary depending on the medication. Some common side effects include nausea, tremors, weight gain, insomnia, loss of appetite, and a decrease in sexual desire. Some people become discouraged by the side effects and stop taking their meds. While many of these side effects can be uncomfortable, the consequences of dropping the medication will likely be much worse. But if the side effects are so debilitating that they actually are as bad as or worse than the illness itself, look for alternatives. Make an appointment with the mental health professional and keep searching for a medication that minimizes the side effects as it manages the mental disorder.

Other reasons people give for quitting their meds include difficulties getting refills, forgetfulness, inconvenience, and, with some drugs, the lowering of emotional "highs." While these reactions may be understandable, none of them is worth the consequences. Mental disorders are rooted in chemical imbalances, and medication is needed to right the balance. Medication is the keystone of the nine strategies: without it, the others may be ineffective. Let the motto "Take your meds" become your loved one's mantra.

Family and friends of a person with a mental disorder can play a crucial role in helping that person stay on the medication. There may be times when a loved one cannot make sound decisions, and family and friends have to make decisions for them. They need to know what the medication is, the correct dosage and frequency, where it is kept, how to get refills, what the side effects are, and whom to contact if necessary. They need to insist gently but firmly that their loved one must take it, and they need to monitor behavior so they can observe the impact of the drug.

In short, they need to be as informed about the medication as the person who takes it. They need permission from their loved one to have access to medical records, including medication information. The loved one may need to sign a document (usually available from a behavioral health care provider) that grants this access to a family member and/or trusted friend. Once this permission is granted, family and/or friends must talk to the doctor

to learn about the medications and how they work. They must also know what signals to look for that might indicate that the drug is losing effectiveness or perhaps that the loved one has stopped taking it.

Above all, they must accept this reality: if the loved one has been diagnosed and prescribed a medication, it is absolutely necessary to take it. Even if the loved one argues against this need, even if the loved one becomes unstable, even if the loved one refuses to take the meds at a later time, family and friends must firmly, kindly, and patiently insist on continuing the medication.

To help prevent this potential conflict, it is wise for the family to discuss the "Take your meds no matter what" strategy with the loved one in advance, even when the loved one is in agreement with it. Being prepared emotionally and intellectually is the best way to handle the consequences of an unmedicated episode when it arises.

During a stable time, tell your loved one that you're committed to monitoring his or her meds, but that you don't want to nag. (There is a fine line between monitoring and nagging. Learn that difference.) You value independence and personal responsibility, but you know how essential this strategy is. You love them to the point of "meddling" in their lives for the sake of this strategy. It is more important that they continue their medication than it is for you not to meddle.

Ask your loved one to help plan ahead for this possibility. If the loved one refuses meds in the future, can you force the person to take them? Can you hide the meds in the person's food or drink until they stabilize again? Can you take the person to the emergency room or treatment center? Ask these questions and discuss these issues in advance. Establish a contingency plan so you don't have to make these decisions during a crisis.

Building a relationship based on trust and respect is essential for effective monitoring of medications; we will discuss this further in later chapters. For now, simply know that it is your vital role to do whatever it takes to help a loved one find the right medication and continue to take it as directed.

The Cost of Medication

Medication is expensive, especially measured over the course of a lifetime. Insurance covers some of it, provided the person is eligible and can afford the premiums. Even then, the co-pay cost is often a major budget item. At some point, family and friends may have to absorb some of the cost.

Many people with a mental disorder become eligible for state programs that include distribution of medication. Inpatient, outpatient, and disability programs offer consultation and medication free of charge, or for a minimal fee. But government funding for mental health is often a low priority for federal and state budgets. What patients need is a careful, ongoing analysis of their treatment options. What they often get instead are brief visits to an array of doctors, conflicting prescription philosophies, revolving medications, and continuing experimentation with new or different drugs. The professionals offering these services are often caring and conscientious, but they work in an underfunded and unreliable system.

Drug costs are a tangled problem for both the patient and the mental health system. Researching and developing new, more effective drugs is crucial but expensive. But the cost of *not* doing it is even greater in terms of human life and productivity—and even in dollar terms, when compared with the potential money saved over time by more effective, targeted medications.

Taking Medication Is Normal

Find the medication needed for a balanced life, take it, and keep taking it: this is the primary strategy that makes it possible to work on the other strategies. All nine can then coalesce into a program that makes a balanced life attainable for someone with a mental disorder, and for that person's family and friends.

Another way to say it is that taking medication is normal for a person with a mental disorder. People without a mental illness have a different "normal," one that does not involve these drugs.

But a mental disorder dictates a new normal, one that includes medication. For people who need insulin to control their diabetes, "normal" means taking insulin; likewise for people who need daily medication for their heart, blood pressure, or kidneys. Many people need medication to be normal. The same is true for people with mental disorders.

What is our message to our loved one who needs medication? One way to say it is this:

> *Take your meds. Always, take your meds. Don't second-guess your need to take your meds. Monitor your meds and the effect they have on you, but never stop taking them. Talk to your doctor about your meds, be open and honest with your family and friends about your meds and their impact on you, but take your meds. Never run out of your meds. Your meds make it possible for you to have a balanced life, so they are your most important medical strategy. There are no exceptions or substitutions: Take your meds.*

STORIES OF Hope

Staying on Meds

My twenty-six-year-old daughter was in a frightening manic phase of her bipolar disorder. Unknown to us, she had stopped taking her lithium months earlier, and now her world was full of bizarre fantasies, racing thoughts, unfathomable conversations, and dangerous relationships. Earlier, she had been generally faithful to taking her medication, saying she knew it was critical to maintaining balance in her life. She told us later that she had gradually stopped her lithium because of hand tremors, some weight gain, and her desire to feel "just

a little manic." She felt she could monitor and manage her manic tendencies herself.

But it didn't work. She wound up struggling to re-register for her last semester in college, and I had joined her to help her find a new apartment and get settled. One night, she couldn't sleep. I was awake with her until midnight, visiting with some of her friends, but then she left around 2:00 a.m. to take a walk alone. She was gone all night. I was frantic. When she calmly strolled in at 7:00 a.m., she said she had a wonderful night and, by the way, this whole episode was being filmed remotely by her boyfriend in another state to be shown as a documentary on PBS.

She was scheduled to see her psychiatrist (who was out of town) in a few days, but I knew my daughter was in danger and I couldn't keep up with her. She needed medication. So I called her counselor, a wonderful woman who was very helpful to our whole family. The counselor and I arranged to meet at the local hospital emergency room with my daughter to begin the meds immediately. When we arrived at the hospital, my daughter protested taking one of them, but the counselor and I ultimately persuaded her to trust us and take it. It took some weeks, but with the medication, counseling, and family encouragement, she gradually came out of her manic phase.

The battle against her mental health problems was not over, but at that point, we made progress. We would still struggle to find the most effective combination of meds and dosages, but she never again experimented with quitting a prescription. I learned once again that I had a responsibility to do whatever I could to convince her to stay on her meds and to talk honestly with her psychiatrist about her compliance. Without medication, little else can be accomplished.

Finding the Right Meds

The struggle to find the right medication for our depressive son took years. The psychiatrist first put him on a low dose of an antidepressant, but it didn't seem to help him much. After a few months, the doctor upped the dosage, and our son began to come out of the depression. One of the side effects was nausea, and when it didn't go away after a few weeks, the psychiatrist switched him to another antidepressant.

The new medication seemed to work pretty well except for some side effects: our son couldn't sleep regularly, had some tremors, and complained about dry mouth. In time, he was feeling better despite the side effects, and he thought he could ease those effects by reducing his dosage. For the first month or so, he seemed to be doing okay. But then the depression came back, and it was very difficult to convince him to see the psychiatrist and his counselor about another medication change. Eventually he did get a different medication and, after experimenting with the dosage for a few months, the doctor found a combination of medication and dosage that let him function both at work and at home very well. That was about two years after his original diagnosis.

We finally felt that this piece of his treatment was in place. But unfortunately, three years later, he started slipping into another depression. First the doctor upped his dosage. But when that didn't have as strong an effect as we had hoped, he once again switched meds. This time it was a newer drug, and it did help enough to stabilize him.

After six years, our son is still functioning well, has a fine job, and is married with one child. He is committed to staying on his medication, his wife is very

supportive, he sees his counselor regularly, and the future looks bright.

What we learned about medication in the past ten years is that the search for the right choice of drug and dosage takes a lot of patience and attention. Fortunately, our son eventually learned the same lesson. But we also learned not to be complacent. The drug may lose its effectiveness, or a serious side effect such as liver damage may emerge, or the person may decide he no longer needs to take it.

We are certainly grateful for our son's current state of mind, but we are always concerned that things may change. We know that it takes more than medication to live free of depressive symptoms. But the medication is a foundation. Without it, we feel his life, and therefore our own lives, would be more difficult and dangerous.

A Different Drummer

Little did my husband and I know what we were facing when we had our third child. We expected a normal childhood, but his was anything but. Today he'd be classified as ADD or ADHD—but back then they just called him a troublemaker. To us, he just always marched to a different drummer. As a baby he rocked and bumped his head in the crib so hard that it walked across the room; as a thirteen-year-old he used pot—he was always a little different from his siblings. In the 1970s, we were told that using pot was just like the beer drinking of our own teen years, but no one told us it would progress from pot to meth to crack.

Now, as an adult, our son has lost everything: wife, child, business. He lives with us and is trying to pull himself out of the hole he has dug. His daughter comes to visit and it is hard for her to understand

the inevitable relapses. We have been through suicide threats and attempts. We have handled all his money as if he were a child; ultimately bankruptcy was unavoidable. Our son drifts from job to job, and even though he sees a counselor, it is still difficult for us to understand why he can't settle down and stay with one job. His dad and I are trying to be understanding and helpful, but our son needs to be a responsible adult and grow up. How are his problems linked together? Are the addictions rooted in his depression and hyper personality problems? We don't know.

At this point, he has finally stopped blaming us, at least openly, for all his problems. He is on Wellbutrin for depression, and that seems to have also stopped the urges to use. Will it help forever, or is this a stopgap? Is another relapse coming? It is hard not to be bitter, but it's also easy to love him. We want him to be like his siblings and be a responsible adult. We will not always be here, and his siblings' anger will be hard for him to overcome. We just pray that the medication continues to help him and that God will take care of him.

"I Just Want to Die"

I'll never forget the day my ten-year-old son came home from school, dropped his book bag, crawled under his bed, and announced, "My life is terrible; I just want to die." It broke my heart to see my intelligent, attractive, compassionate little boy feel so overwhelmed by his declining self-esteem, and his mounting social problems at school, that he was giving up on life at the ripe old age of ten. I tried everything I could think of to coax him out from under the bed—argument, logic, compassion, humor, ordering him out, offering a hug, a fun movie, even my ace in the hole—ice cream and cookies—but

nothing worked. He had had enough, and now he just wanted to die. I tried joking with him and pulling on his legs to get him out. He clung tenaciously to the bed frame and I succeeded only in moving the bed with him underneath it.

The fact that his emotional pain was so debilitating was a bit less frightening to me, perhaps, because I had lived with it myself, and I could name it. At age ten, I had also begun a battle with depression—a battle that, despite my stubbornness, I could not win without medication. Clearly my son was now engaged in this same battle, and I did not want him to have to fight it alone for thirty years as I had. I knew my son needed my support, medicine to regulate his brain chemistry, and counseling to improve his self-esteem—in that order. But his most urgent need was to see some shred of hope and hold on to it until we could get in to see a psychiatrist and counselor.

With all of my other ideas and options exhausted that afternoon, I finally asked him what he wanted me to do. He said he wanted me to leave—he wanted to be alone. This seemed a bit of a risky option to me, but I could think of no others. I removed every sharp object from his room, closed the door, and gave him just a few minutes alone.

When I returned to his room, his window was open and he was gone. I panicked. Was he running to Main Street to throw himself in front of a car? Was he fleeing into the woods across the street in an effort to run away from his feelings? I ran around the house, calling for him, praying for the wisdom—or luck—to find him quickly. Before long, I caught sight of him in the yard, high up in a fir tree, where he had climbed to ensure his privacy. I kept watch on his position from the living room window, and I went out to meet him when he finally climbed down. (He was hungry.) Over

a snack, we talked about what depression was, that it was an illness that made you feel really bad about yourself, and that much of what it made you feel was a lie—he was not stupid or worthless, but his brain chemistry made him feel that way.

It took three very long weeks before we could get in to see the psychiatrist. After taking the medication prescribed by the psychiatrist for a couple of weeks, my son began to feel much better. I felt blessed that he had been willing to listen to me, and to trust both me and his doctor to find a way out of those feelings of pain and hopelessness.

I felt equally blessed that the medication that had successfully restored my own brain chemistry also worked for his.

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QUESTIONS FOR GROUP DISCUSSION OR PERSONAL REFLECTION

1. Have you discussed the need for medication with your loved one? If so, what were the results of the conversation? If not, do you plan to initiate this discussion soon?
2. If your loved one needs medication for a mental disorder, has taking the medication been difficult for him or her? If so, how?
3. How do you see yourself as an advocate for your loved one?
4. At what stage did you receive an accurate diagnosis of the mental illness?
5. Does your loved one take an effective medication at this time? How is it helping?
6. What are the side effects of this medication?
7. What is your loved one's history with medication?
8. How do you describe your role in meeting and monitoring your loved one's medication needs?

9. What are your feelings about the mental health professional who prescribes this medication?
10. List your positive and negative experiences in the search for the "right" professional and the "right" medication.
11. To what extent has your loved one stayed on the medication? If he or she has quit taking it, what were the reasons? What were the consequences?
12. How do you handle the cost of the medication?
13. "Medication is the primary strategy for coping with mental disorders": what does this statement mean to you?
14. If you saw no way to convince your loved one to take medication—if the person denied having the disorder—what would you do?

CHAPTER TWO

Counseling

STRATEGY 2 *Urge our loved one to maintain a supportive relationship with a therapist, counselor, or sponsor.*

This strategy is aimed at helping your loved one benefit from the talking and listening that professional counselors do. Counseling goes hand in hand with medication in treating the symptoms of mental illness. Sometimes the psychiatrist or other professional prescribing the medication also assumes the role of therapist or counselor. But more often, a counselor serves that purpose, meeting regularly with the client and also staying in touch with the prescriber to share information.

For our purposes here, the terms "therapist" and "counselor" are interchangeable. They both describe someone who has some educational credentials in psychology and who usually charges a fee to work with clients who are diagnosed with mental illness. The credentials could range from a masters or Ph.D. in social work, psychology, or other therapeutic discipline, to an M.D.