

How Siblings and Offspring Deal with Mental Illness

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THE TROUBLED JOURNEY OF SIBLINGS AND OFFSPRING

Mental illness has a profound impact on all members of the family, including young siblings and offspring. The disruptive force of mental illness is often referred to as family burden. This burden has a subjective component, which consists of the emotional consequences of the illness for other family members, and an objective component, which consists of their everyday problems.

At the core of the subjective burden is a powerful grieving process. Family members may mourn for the relative they have known and loved before the onset of the illness, for the anguish of their family, and for their own losses. In addition, family members are confronted with an objective burden—the daily problems and challenges that accompany the mental illness.

Family members must learn to cope with symptoms of the illness, with caregiving responsibilities, with the limitations of the mental health system, and with social stigma. Young family members are especially vulnerable to disruptive or traumatic events, such as the mental illness of a close relative. Compared with adults, children have more limited coping skills and strategies, are more dependent on the other people in their lives, and have fewer psychological defenses. Moreover, early developmental accomplishments provide the foundation for later ones, and delays or disruptions in development may have long-term consequences, including a residue of “unfinished business” that reverberates through future years.

Our research with adult siblings and offspring suggests a significant relationship between age at the onset of a relative's mental illness and its impact. In essence, the younger the family member, the greater the potential impact. One woman says: "I became the perfect child to spare my parents more grief. I was forced to become responsible . . ."

Mental illness has a pervasive impact on siblings and offspring during their early years. For example, young children may become enveloped in their relative's psychotic system, with lasting consequences for

their own lives: “My mother has been sick practically my whole life. It is hard for me to decipher which of my experiences are ‘normal’ and which are not.”

As the illness consumes their family’s energy, young family members may feel that their own needs are neglected or that they grow up too quickly. Their family relationships are also affected, and they may assume a parental role that places heavy responsibilities on their immature shoulders. In the words of one family member, “I feel like I missed out on being a kid.”

Siblings and offspring may be subject to a “survivor’s syndrome” that exposes them to feelings of guilt for having been spared. In addition, there may be adverse effects on their academic life and peer relationships. For instance, these family members may experience a sense of social deviance, have difficulty straddling the different worlds inside and outside their family, and be reluctant to bring friends and dates to an unpredictable home environment.

Even after they leave home, siblings and offspring carry a legacy that permeates all the crawl spaces of their adult lives. This legacy has personal, interpersonal, occupational, and family components. Their personal legacy colors their feelings about themselves, and they may experience problems with identity and self-esteem that leave them unsure of themselves and uneasily dependent on the approval of others. They may also develop an excessive need for perfectionism and control to compensate for their chaotic and unpredictable family situation. Often, they have concerns about their own mental health.

Their interpersonal legacy imprints their adult relationships. Possible problems include feelings of social alienation and isolation, difficulty with trust and intimacy, inappropriate continuation of a caregiving role in close relationships, and reluctance to make long-term commitments.

Their family legacy has many elements. Adult siblings and offspring may enter an early marriage to escape their troubled family or may delay or avoid marriage in light of their unresolved issues. When they do marry, they may worry about the mental health of their own children and are likely to struggle to balance their commitments to their two families. Almost universally, siblings and offspring worry about caregiving responsibilities.

In addition to the family burden, siblings and offspring are at risk for a traumatic reaction that causes intense emotional and physical distress or even for a posttraumatic reaction that persists for many months or years. Posttraumatic symptoms may include heightened fears and anxieties, recurrent images or thoughts, intrusive flashbacks, emotional numbing or constriction, loss of interest in normal activities, and withdrawal from other people.

However, aside from these risks, it is also clear that siblings and offspring have the potential for a resilient response to this family tragedy. In the words of one family member, “I can now say that, like that old aluminum foil ad, I am ‘oven-tempered for flexible strength.’” Resilience comes at a high price, however, and is usually accompanied by intense feelings of anguish and loss.

During their childhood, adolescence, and adulthood, adult siblings and offspring share three core needs with other relatives.

First, these family members need information about mental illness and its meaning for their family. This knowledge also facilitates the process of “naming and taming” an illness that is often incomprehensible and frightening to family members.

Second, siblings and offspring need skills to cope with the mental illness and with its impact on their own lives. For example, they need to learn to deal with the symptoms of their relative’s illness and with their own anxiety and stress.

Third, they need support for themselves. As one family member remarked, “The isolation was profound.” Support must be sought from family, friends, professionals and other service providers, and NAMI.

In addition to their need for information, skills, and support, many siblings and offspring face a special

challenge—to recognize that their needs and desires matter! So often they deny or minimize their own needs in their effort to meet the needs of their family.

Adult siblings and offspring share many other concerns. Concerns cited most frequently: concern about caregiving for their relative (94%), family disruption (83%), difficulty balancing personal and family needs (81%), feeling their own needs had not been met (79%), feelings of helplessness and hopelessness (75%), poor self-esteem (75%), guilt feelings (74%), psychic numbing (70%), problems trusting (69%), problems with intimacy (69%), a sense of growing up too fast (67%), and personal depression (66%).

During childhood, the period of greatest need, siblings and offspring have limited resources to assist them in coping with this cataclysmic event. Nevertheless, in spite of their struggle, ultimately most siblings and offspring do adapt to the mental illness in their family, often developing impressive qualities along the way.

As noted, siblings and offspring have compelling needs from the time that mental illness appears in their family. We need to reach out to young family members early and to continue to address their changing needs throughout their lives. Siblings and offspring need three kinds of services: those that can meet the needs of their relative with mental illness, those that can strengthen their family as a unit, and those that can address their own needs.

Obviously, siblings and offspring benefit from a comprehensive system of community-based care that assists people with mental illness in leading productive and satisfying lives. Such a system of care enriches family life as well. In addition, siblings and offspring profit from services that strengthen their family as a unit.

Finally, siblings and offspring have their own special needs. Here are some suggestions for meeting the needs of siblings and offspring:

- Strengthen and support the family system as a unit. A wide range of resources and services may be helpful under these circumstances, including improved services for people with mental illness, respite care during periods of crisis, family education and support, and special assistance for young family members.

- Learn about the family experience of mental illness, the unique issues and concerns of siblings and offspring, effective coping skills and strategies, and helpful services.

- Reach out as early as possible to young siblings and offspring, who are profoundly affected by the mental illness of a beloved relative. Listen to their stories. Encourage them to ask questions and share their feelings. Tell them that they are not to blame.

- Meet the needs of young family members in an age-appropriate manner. Like other family members, children and adolescents need information about mental illness, skills for coping with the illness, and support for themselves. Such needs can be met by relatives, by caring people outside the family, by professionals, or by school personnel. For example, schools might provide educational programs about mental illness for a group for students who are dealing with mental illness at home.

- Offer professional counseling for siblings and offspring who are experiencing particular difficulty. Play therapy can be helpful for young children, who have difficulty expressing their concerns verbally. Older children may benefit from individual or group therapy, as may adult siblings and offspring. More than three-fourths (77%) of survey participants had received personal therapy. Almost all reported that it was helpful.

- Assist siblings and offspring of all ages in maintaining the integrity of their own lives and in developing constructive long-range plans. They often need reassurance that their needs matter and that they will be supported in achieving their goals.

Diane T. Marsh, Ph.D., Professor of Psychology, University of Pittsburgh at Greensburg

WHAT CARING ADULTS CAN DO FOR THE CHILD WHOSE PARENT HAS A MENTAL ILLNESS

Tell the child what illness their parent has, its symptoms and prognosis. Discuss the medications their parent will be taking. Give them as much information, at an age-appropriate level, as they seem to want to have. It is very frightening to be kept in the dark.

Give the child frequent opportunities to discuss his fears, questions and concerns.

Listen to the child without judgment. Assure the child that all of his feelings are valid and okay.

Make reading material available. For a young child, reading together creates a positive atmosphere for further discussion and questions. But for the older child, leave the material in an accessible place and allow the child to read when they are ready. Don't push or question. The child may be uncomfortable talking about the subject (or feel disloyal to the ill parent).

Whenever possible, allow the child to participate in decisions that affect the whole family.

Create opportunities for the family to be "normal." For example: Going to church together, taking a vacation or holiday, going school shopping. It is difficult to feel "normal" when your parent has mental illness.

Recognize the child's accomplishments in school, sports, music, etc. Encourage the child to participate in activities that are important to them personally and to develop their own talents.

Let the child know that it's okay to have fun, that their ill parent would want them to have a normal, happy life in spite of the family situation.

Assign the child an appropriate level of responsibility in the care of the home, other siblings and the ill parent. Children can be so anxious to help that they will take on an overwhelming burden of responsibility. It is up to adults in their life to know how much is too much.

See that the child understands that no matter what caretaking role she has, the child is in no way responsible for the onset of the illness, its symptoms, severity or ultimate outcome. No child can control mental illness, but many believe that they can if only they work hard enough at it.

Share the work to be done among all siblings, according to their ability to participate. Too often one child becomes the caretaker. All children need to feel involved.

If the parent is hospitalized, give the child the option to visit or not. Psychiatric wards and state hospitals can be very frightening to a child. They are exposed to other very ill patients besides their own parent, not to mention barred windows, locks and fences.

If your child chooses to visit, prepare her in advance as to what to expect. Explain what she will see and why. Talk about it afterwards.

Talk about what happens in the hospital, the treatment their parent will receive, how long they will be hospitalized, what to expect when the parent returns home. Be realistic.

A talk with the parent's doctor may be reassuring for the older child. Also, it may give the child an opportunity to ask questions that they would hesitate to ask a parent.

Take steps to ensure the safety of the child at all times. While most persons with mental illness are not violent, the unpredictability of the illness may make the child feel threatened. A child experiences so much guilt about even having this fear of their own parent that he is not likely to mention it. Make arrangements for the child before and after school and give serious thought before utilizing a child as a sitter for the mentally ill parent.

Learn coping skills as a family. There are more effective ways to communicate with a person with psychosis. Help the child with this.

As a parent recovers from a psychotic break, there is a readjustment and reintegration into the family. The older child may have difficulty accepting the return of "mom" or "dad." Talk this out as a

family. Recognize how this will impact the children in the family.

Make sure that the family is represented at the child's important occasions such as graduations, religious ceremonies and recitals.

Encourage children to join a professionally-led, age-appropriate support group, available in some communities.

Offer physical affection regularly. A hug or a smile may be really needed.

Foster a sense of humor. Mental illness is serious and tragic, but a sense of humor can be a valuable tool for coping with the bizarre behaviors that accompany delusions and hallucinations.

By Cathy Aines, former Executive Director, NAMI Vermont (1992). Reprinted from NAMI's Family-to-Family Education Course

Editor's Note:

We would also like to note that children can be very resilient and can do well with proper coping mechanisms.

COPING TIPS FOR ADULT CHILDREN AND SIBLINGS

If you find it difficult to come to terms with your sibling's or parent's mental illness, there are many others who share your difficulty. Most siblings and adult children of people with psychiatric disorders find that mental illness in a brother, sister, or parent is a tragic event that changes everyone's life in many basic ways. Strange, unpredictable behaviors in a loved one can be devastating, and your anxiety can be high as you struggle with each episode of illness and worry about the future. It seems impossible at first, but most siblings and adult children find that over time they do gain the knowledge and skills to cope with mental illness effectively. They do have strengths they never knew they had, and they can deal with situations they never even anticipated.

A good start in learning to cope is to find out as much as possible about mental illness, by both reading and talking with other families. NAMI has books, pamphlets, fact sheets, and tapes available about different illnesses, treatments, and issues you may have to deal with, and you can join one of the 1,200 NAMI affiliate groups throughout the nation. (For other resources and to locate your state or local NAMI affiliates, call the NAMI Helpline at **(800) 950-6264**.)

Here are some things to remember that should help you as you learn to live with mental illness in your family:

You cannot cure a mental disorder. No one is to blame for the illness.

Mental disorders affect more than the person who is ill. They affect the entire family.

Despite your best efforts, your loved one's symptoms may get worse. But they may also improve.

If you feel extreme resentment, you are giving too much.

It is as hard for the parent or sibling to accept the disorder as it is for *other* family members.

True acceptance of the disorder by all concerned may be helpful, but it is not necessary.

A delusion has little or nothing to do with reality. Delusions do not respond to reason.

Separate the person from the disorder.

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

The illness of a family member is nothing to be ashamed of. The reality is that you will likely encounter stigma from an apprehensive public and other family members.

You may have to revise your expectations of the ill person, as well as of yourself and others.

You may have to renegotiate your emotional relationship with the ill person.

Acknowledge the remarkable courage your relative may have shown when dealing with a mental disorder.

Generally, those closest in sibling/offspring order and gender become emotionally entangled while those further away in age or of another gender may become estranged.

Grief issues for siblings are about what you had and lost. For adult children, they are about what you never had.

After denial, sadness, and anger comes acceptance. The addition of understanding yields compassion. It is absurd to believe you can correct a biological illness such as diabetes, schizophrenia, or bipolar disorder with talk, although addressing social complications may be helpful.

Symptoms may change over time while the underlying disorder remains.

You should request the diagnosis and its explanation from professionals.

Mental health professionals have varied degrees of competence.

You have a right to ensure your personal safety.

Strange behavior can be a symptom of the disorder. Try not to take it personally.

Don't be afraid to ask your sibling or parent if he is thinking about hurting himself. Suicide is real.

Don't shoulder the whole responsibility for your mentally disordered relative yourself.

The needs of the ill person do not necessarily always come first.

If you can't care for yourself, you can't care for another.

You are not a paid professional caseworker. Your role is to be a sibling or child, not a parent or caseworker.

It is important to have boundaries and to set clear limits.

If a mentally disordered relative has limited capabilities, it doesn't mean that you expect nothing of him or her.

Many times capabilities change with the severity and ups and downs of the illness. Look for current strengths and never give up hope for improvement.

It is natural to experience many and confusing emotions such as grief, guilt, fear, anger, sadness, hurt, confusion, and more. You, not the ill person, are responsible for your own feelings.

Inability to talk about your feelings may leave you stuck or "frozen."

You are not alone. Sharing your thoughts and feelings and getting practical suggestions from a peer support group is helpful, enlightening and empowering.

With education and support, you may see the silver lining in the storm clouds as you gain: increased awareness, maturity, sensitivity, receptivity and compassion. You may become less judgmental and self-centered: a better person.

Mental illness is not on a continuum with mental health.

Seek out the best experts available in your community.

Ask for a joint conference with the treatment team and the adult patient, showing concern for confidentiality.

Always be prepared for a crisis but never, never give up hope!

Reprinted from www.nami.org, with some additions from the NAMI Family-to-Family Education Program and NAMI members.

OBJECTIVE LIFE BURDENS OF ADULT SIBLINGS AND CHILDREN OF PEOPLE WITH MENTAL ILLNESS

In the NAMI Family-to Family Education Program, different "relative groups" discuss the objective burdens each group bears. Adult siblings and adult offspring consistently report the following issues:

Disproportionate attention being given to the ill sibling or parent; an atmosphere of secrecy, confusion,

silence, shame; witnessing terrifying psychotic breaks and personality changes in a mentally ill family member.

Being menaced or hurt by someone who is supposed to be a caring, protective family member; experiencing the sibling or parent as “bad” rather than “ill.”

Bearing the social stigma of having a “strange” family member.

Handling the emotional needs of the caretaking parents or the neglected well-parent spouse.

Having more chores and responsibility; having to “grow up fast;” needing to be a “super” child to “make up” for the ill parent or sibling.

Worry that you caused the illness, or that you will get the illness, or you will make the parent or sibling worse.

Worry about how much you should do for the ill family member; worrying about the time when the caretaking parent or parents die and it will all be your responsibility.

MEETING THE NEEDS OF YOUNG FAMILY MEMBERS OF SOMEONE WITH A MENTAL ILLNESS

Mental illness is a catastrophic event for the family system that affects all family relationships and all members of the family. A wide range of resources and services may be helpful under these circumstances, including improved services for the family member with mental illness, respite care for family caregivers, support for adult members of the family, and special assistance for young family members.

Coping with early onset of a brain disorder in a child or adolescent is a daunting experience for parents, but too often other family members, especially the children, tend to get overlooked, or are protected from knowing the truth of their sibling’s illness or even a concrete diagnosis. Frequently these siblings grow up blaming themselves, feeling neglected and unloved by their parents, or fear that this terrible illness can somehow be contagious or inherited by their own offspring. It is important to strengthen and support the family system as a unit, providing the services necessary for meeting the needs of all family members. Here are some suggestions on ways to support all the young family members needs during these trying times.

FIND BOOKS AND ARTICLES ABOUT THE EXPERIENCES AND NEEDS OF SIBLINGS AND OFFSPRING OF PEOPLE WITH MENTAL ILLNESS.

Many resources are available, including books for young children who have a close relative with mental illness. There are also books and articles for adult family members, such as the spouse or parents of the ill relative, that may assist them in meeting the needs of young children in the family. Call the NAMI Helpline at (800) 950-NAMI. Request a list of suggested books and publications.

REACH OUT TO YOUNG SIBLINGS AND OFFSPRING AS EARLY AS POSSIBLE.

All young family members are profoundly affected by the mental illness of a beloved parent or sibling. There is no way to shield children from this family event, but the negative consequences may be diminished if there is open communication within the family and continuous attention to their needs. Encourage young family members to ask questions and to share their feelings with you. Reassure them

that they are not responsible for the illness.

MEET NEEDS FOR INFORMATION, SKILLS, AND SUPPORT IN AGE-APPROPRIATE MANNER.

As with other family members, young family members need information about mental illness and its treatment, strategies and skills for coping with the mental illness and its consequences for their family, and support for themselves. These needs may be met by adult members of the family, by caring people outside the family, or by professionals.

FORM A NETWORK OF PARENTS AND PROFESSIONALS COMMITTED TO MEETING THE NEEDS OF YOUNG FAMILY MEMBERS.

Many other family members share your concern for children and adolescents who are growing up with mental illness in their families and can offer valuable suggestions for meeting their needs. Similarly, professionals who work with children and adolescents can offer consultation and services.

Maintain a life span perspective that acknowledges their changing needs at different stages of development; seek out services or develop services if none are available. A full range of services for families consists of non-clinical services, including educational programs and support groups, and clinical services, including various forms of psychotherapy. All of these services offer potential benefits for family members at all stages of development.

Work to develop a specialized staffed support group that provides information about mental illness, practical advice, and contact with other young siblings or offspring of consumers of mental health services. Young family members can benefit from a group or other activities designed specifically for them. Groups can be offered for elementary, junior high, or high school students, and can be located in a variety of settings, including a local NAMI affiliate, a school, or mental health clinic.

Consider personal counseling for young family members who are experiencing special difficulty. Some young family members may experience intense and unresolved problems in response to the mental illness in their families. Although they are likely to benefit from a specialized group or program, these family members may also profit from personal counseling with a child or adolescent therapist. Your child's teacher, guidance counselor, or pediatrician can help you decide whether personal counseling is appropriate for a particular child or teenager.

Encourage programs in schools that can educate the school population about serious mental illness. Given the incidence of serious mental illness, there are legions of children and adolescents who are living with mental illness in their families. Enlist the assistance of teachers, principals, guidance counselors, and school psychologists, who can serve as a support system for young family members. NAMI disseminates SOS: Stamp out Stigma, an educational curriculum about mental illness. *[Contact NAMI for more information.]* This will be an important tool for educational professionals to help siblings as well as other family members of the mentally ill.

Help young family members understand and adapt to the mental illness in their family. Adaptation to mental illness requires many coping strategies and skills. For example, young family members need to understand the impact of mental illness on their own lives, to establish realistic expectations for themselves and other family members, and to develop an appropriate relationship with the relative who has mental illness.

Assist them in maintaining the integrity of their own lives and in developing constructive long-range plans. Mental illness in the family often functions as an energy sinkhole consuming valuable energy needed by young family members for their own development. It is essential to support them in functioning effectively in their school work, in their peer relationships, and in activities outside the

family. They often need reassurance that their needs matter and that they will be supported in achieving their goals.

by Diane T. Marsh, Ph.D.

PARTICIPATING IN AN NIMH SCHIZOPHRENIA SIBLING STUDY: One Family's Journey Toward Hope

It has been almost a year since our family found a description of a schizophrenia sibling study in the *NAMI Advocate*. This research is an ongoing study of the National Institute of Mental Health (NIMH), in Bethesda, Maryland, comparing the genetic and neurobiological differences among hundreds of people with schizophrenia or schizo-affective disorder and their siblings.

Of eight siblings, I am the only one with a schizo-affective disorder. Our family applied to the sibling study knowing that this research is generating information to give neuroscience the keys that are beginning to break into the complex biological codes of this terrible illness. My brother Michael's business is providing computer technologies to researchers studying the genetic abnormalities within the full and immensely complex human genome. Michael recognized the neuro-imaging and genetic technologies of NIMH as the most advanced tools of neuroscience in the world.

This study was an opportunity for eight siblings to add an unusual wealth of information to schizophrenia research. We embraced the opportunity to benefit others with this disorder. We were accepted into the study and were welcomed by NIMH as respected and valued partners in this pioneering research. They arranged our flight schedules, hotel bookings, and testing days to maximize the rare time we had to spend together. The study was a fast moving two days of detailed magnetic resonance imaging (MRI) scans, interviews, and neuropsychological testing. Other than a routine blood draw, there was no invasive testing.

For our family, the long road to the sibling study began 28 years ago in 1975. I was hospitalized after a three-year slide into a psychotic illness. I fell into the hands of a psychiatrist who psychoanalyzed my hallucinations and assessed my entire family as "schizophrenogenic." Despite the neurobiological anarchy sweeping through my life like a forest fire, reality began to dawn on me by 1979: I had seven brothers and sisters, and none of them were like me. They were all working, going to school, or in college. We were of the same parents, and we were all raised by a courageous and hardworking single mother who loved us all. I was different from early in life. As a young adult, hallucinations and depression were taking over my entire life.

None of my siblings had ever been brought to their knees as I had by visions and voices and depression that paralyzed even my will to live. I knew my family was not doing this to me; there was something wrong with my brain. I found another psychiatrist, who remains with me to this day as a constant source of expertise and encouragement.

Looking back from 2003, I call the primitive and hopeless psychiatry of the 1970s the "dungeons of the day." Old Freudian ideas that had twisted the psychiatry of schizophrenia away from the brain onto blaming families were still widely held. It was a dated era still spun with mythically monstrous mothers named and blamed as "schizophrenogenic."

The psychoanalytic psychiatry of the 1970s perpetuated the influence of a century of Freudian ghosts that linger to this day as the deep shroud of shame, guilt, and misunderstanding that continues to obscure the neurobiological legitimacy of this illness.

Before we left NIMH, I talked to Dr. Michael F. Egan, the lead investigator of the sibling study. I told him what it was like for me coming from the "dungeons of the day" to be, 28 years later, working with the NIMH as a full and respected partner in research that I thought I would never see happen in my lifetime.

Dr. Egan told me that they have good evidence directly from the sibling study that five or six genes

increase the risk for schizophrenia. The empowering character of this progress is a clear and bright light of new hope and promise moving at light speed in the right direction. It is a privilege to be a part of this revolution in neuroscience.

At NIMH, I saw my brothers and sisters in the full light of their loyalty and love. They were all indicted as "schizophrenogenic" 28 years ago, but when this illness threatened to take me away from them, they rose to the challenge and held out their hands to me in the moments I otherwise would have drowned. Six of them were younger than I was when this illness swept out of hell, yet they have traveled this distance with me unafraid. They have made my life richer, funnier, and filled to overflowing as a sister, an aunt, and a friend.

Without them, it would have been a dark and difficult journey. With them, we have walked this 30-year road out of darkness into daybreak.

by Peggy Symons, from www.nami.org

HOW PROVIDERS CAN HELP ADULT CHILDREN/SIBLINGS OF PERSONS WITH MENTAL ILLNESS

The following information represents a composite of responses from family members who have participated in NAMI Family-to-Family In-Service training programs, given around the country, to introduce professional providers to the "Relative Groups" in families of individuals with serious mental illness.

HELPING SIBLINGS

Many siblings want providers to listen to them, to ask what they know, think and feel about their ill sister or brother, to let them be involved constructively by helping in some way.

Siblings also need providers to understand and support them when they feel they must step out of the family problem, to empathize when they are torn between the things they need to do to move their own life along and the obligation they feel to help their parents and their ill brother or sister.

Sibling's survival guilt can arouse many fears about their own mental well-being, and influence many of their decisions about life choices. These issues are very real for young adult siblings who are just starting out into the world; they need to talk about these feelings and to explore whether their sibling's

illness might be casting a shadow on any part of their lives.

Oddly enough, many siblings report that providers (and even people in their own families) do not register the enormity of sibling loss, or comprehend the depth of sibling grief. Perhaps this is part of family denial, of parents not wanting to see any more “hurt” children in their family. Perhaps it is the way people neglect survivors’ feelings because, after all, they have been lucky enough to survive. Sibling loss is normally intense and is reactivated at every developmental milestone throughout life. Providers can help sibs with the grieving process at any one of these points.

Siblings tell us that they have commonly blocked the trauma of scenes and events that they witnessed when their brother or sister was critically ill. This includes traumatic things that happened to them, like being threatened or abused. Providers need to understand that siblings who have endured these ordeals often want to detach from the ill sibling, the well sibling can come to understand that these behaviors are illness-related, but it takes time and courage to overcome this kind of trauma.

Many siblings report that they feel invisible in their family after mental illness strikes—that their needs get lost in the intense demands made on the family by their ill brother or sister. Siblings in these families must bear witness to the extraordinary stresses imposed on their parents and often do not want to burden their parents further with demands of their own. Sibling support groups provide a safe and welcome place for well sibs to talk about these issues.

HELPING ADULT CHILDREN

The vast majority of people who are the children of individuals with mental illness do not develop mental illness themselves. It is important for providers to de-stereotype this population, which has often been portrayed as inescapably disordered due to parental dysfunction. Each adult child will have his unique story to tell, and should not be negatively “categorized” due to the circumstances of mental illness in a parent.

However, most adult children will tell you that no one can come through this experience unscathed. Depression, anxiety, feelings of hopelessness and defeat, repressed anger, magical thinking, and passivity all combine to form a persistent dysthymia that can rob life of happiness. Many adult children appear to be exceptionally self-reliant and competent, masking the conflict they have about dependency needs and their reluctance to ask for help; rarely do they allow others to glimpse the sadness and uncertainty they feel inside. Adult children can be greatly assisted by psychotherapy; special support groups are now available, as are educational and self-help books relevant to their family experience.

Studies indicate that having a well parent in the mix, or a sustaining sibling relationship, will mediate the stress involved in coping with an ill mother or father. Without these supports, life for the child is often terrifying and traumatic, and worse if the family must endure the more severe spectrum of illness. Children caught in this situation need networks of support outside the family, and must be helped to create a psychological buffer between themselves and the disordered behavior of their ill parent.

Adult children mourn the loss of their childhood, the loss of a carefree, stable family structure, and the loss of their own young potentials. Many children coming through this hardship are “late-bloomers;” so much of their development and self-confidence is placed on hold while they cope with the disabilities of the parent. Others speak movingly about how odd it feels to outgrow a parent, to develop beyond the capacities of a person you always expected to be “ahead” of you, showing the way. Many report a sense of dread at the prospect of “signing-on” again to care for

the ill parent as the parent becomes older. These conflicts and ambivalences need to be treated with empathy and respect.

Many adults children relate that they were told nothing about what was wrong with their ill parent—that even after growing to adulthood, they are still “in the dark” about the parent’s diagnosis. It is paramount

for mental health professionals to provide education and guidance to children, to help them identify illness behaviors and to consult with them about family decisions made to accommodate the ill parent.

The most important role for providers in helping children of a parent with mental illness is a preventive one—that is, giving the parent sufficient services and supports to keep the illness (and the family) stable. Whenever children are involved in a family with a parent with a serious psychiatric illness, the family should be offered supportive family consultation and family education.

BOOK REVIEWS

SERIOUS MENTAL ILLNESS AND THE FAMILY: THE PRACTITIONER'S GUIDE

by Diane T. Marsh, John Wiley & Sons, Inc., 1998.

Review by Betsy S. Greer & Elizabeth Farrell, NAMI Literature Committee

Family members and facilitators of family education courses will want to take a look at Diane Marsh's book. Marsh, a psychologist, has long been involved with people with mental illnesses and their family members, especially siblings and adult children, and with the training of professionals. This book, aimed at professionals, is the latest of Marsh's work, written independently or co-authored, that the NAMI Literature Committee has recommended.

Serious Mental Illness and the Family focuses on the competency model of families, a model that "emphasizes the family's strengths, resources, and expertise; defines family-professional relationships as collaborative; promotes a sense of familial mastery; and encourages feelings of hopefulness." The chapters are consistently organized, and each begins with a scenario in which the information in that chapter could be used. The chapters contain a wealth of guidance about the needs of families and the kinds of information that will be helpful to them. Many families will find comfort in learning that their needs are universal and will appreciate knowing about the different ways those needs can be met.

Marsh is to be especially commended for her chapters that acknowledge the special needs of spouses, siblings, and offspring—needs often glossed over in favor of emphasis on parents and their adult children. She is excellent in her discussion of confidentiality, noting the legal constraints confidentiality bears, but also realizing that professionals can help caregiving families get the releases that permit them to obtain the information they need to care for a relative. Marsh is also clear that there is a place for psychotherapy (especially for siblings and offspring), but she defines it carefully and differentiates it from the "family systems" therapy of the past that was, and still is, so distressing to family members.

For those facilitating family education, this book re-enforces the value of these courses and serves as a reminder of the issues that individuals face when mental illness affects one of their loved ones. The book also has a section on family action plans, which is a resource for ways families can successfully cope with an ill relative.

The book's \$55.00 price may be prohibitive for some, but this is a book that should be in local libraries and on the bookshelves of our local mental health centers. This reviewer's major regret is the tardiness in which the NAMI Literature Committee learned about the book; the word should have been put out long ago about its value.

Reprinted from www.nami.org

MAD HOUSE: GROWING UP IN THE SHADOW OF MENTALLY ILL SIBLINGS

by Clea Simon. Doubleday, 1997.

Review by Lisa Miller and Kathy Nealen, NAMI Literature Committee

Mad House: Growing Up in the Shadow of Mentally Ill Siblings by Clea Simon is a personal, often

painful account of the author's experiences growing up in an upper-middle class, caring family deeply affected by the mental illnesses, or brain disorders, of her two older siblings. Simon is the youngest in a family of three children. She watched her brother Daniel, 10 years older, decompensate from the bright and admired brotherly caretaker who entered Harvard after high school to a young man ravaged with paranoid thoughts and hallucinations, unable to realize his goals and maintain his role in the family. Her sister Katherine, eight years her senior, was affected at a much earlier age by what eventually evolved into paranoid schizophrenia. She became Simon's unpredictable but regular tormentor in a household that tried naively and fruitlessly to protect the author from the effects of the illnesses of her siblings.

Simon helpfully reports recent findings in the areas of genetics, brain research, and the factors influencing both schizophrenia and bipolar disorder. However, the book's focus and its real strength is the author's depiction of her own experiences as a child and the struggles that continued into adulthood. The effects of mental illness on well siblings has often been overlooked, and coming to grips with the pain of their well children may be too much to add to the extraordinary burdens of a parent dealing with a child with a mental illness.

Clea Simon grew up to attend Harvard herself and to become an accomplished journalist and writer. With the help of professional counseling, she gradually came to understand her experiences and losses and to make positive changes in her life. In *Mad House*, she shares her struggles and growth and gives permission for siblings to have difficulties coping and to seek both group support through NAMI and professional counseling.

Reprinted from www.nami.org

How Siblings and

Offspring Deal with Mental Illness

To order additional copies of this booklet, please contact
NAMI Metropolitan Baltimore at (410) 435-2600 or
namimetrobaltimore@yahoo.com,
or visit www.nami.org/sites/namimetrobaltimore.

To locate state or local NAMI organizations nationwide, or to receive information from the national
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call (800) 950-6264 or go to www.nami.org.

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original publication.

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FOR FAMILIES & CAREGIVERS

NAMI Family-to-Family: a free 12-week course for relatives and significant others of individuals with severe mental
illnesses. The course discusses the clinical treatment of these illnesses and teaches the knowledge and skills that

participants need to cope more effectively.

NAMI Family Support Groups: a 90-minute weekly peer support group for relatives and significant others.

NAMI Basics: a education program for parents and other kinship caregivers of children living with mental illnesses.

FOR CONSUMERS

NAMI Peer-to-Peer: a free course for consumers containing individual relapse prevention planning, a debriefing/storytelling week and an advance directive for psychiatric care.

NAMI Connection Recovery Support Group: a 90-minute weekly support group run by persons who live with mental illness for other persons with any diagnosis who also live with mental illness.

Healthy Hearts & Minds: a multimedia program about, accessible and affordable lifestyle changes designed to reduce cardiac risk among people with mental illness.

FOR PROVIDERS AND THE GENERAL PUBLIC

NAMI Ambassadors: a variety of workshops for community and professional audiences presented by relatives and individuals living with mental illness about: Basics about Mental Illness, Working with Families in Crisis, Children with Behavioral Disorders, What is Recovery? And others.

NAMI In Our Own Voice: a 90-minute interactive, multimedia presentation by individuals with mental illness that offers hope and provides insight into the recovery now possible for people with mental illness.

The foregoing programs are available in the Baltimore metropolitan area. Check with your state or local NAMI to determine which programs are available in your area. To locate state or local NAMI organizations nationwide, or to receive information from the national NAMI helpline or website, call (800) 950-6264 or go to www.nami.org.

NAMI PROGRAMS: