



Family Guide on Mental Illness

November 2016

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WELCOME AND INTRODUCTION

Dear Family Members and Friends:

Serious mental illnesses affect one in five families. Unfortunately, individuals with these illnesses, as well as their families, often hesitate to get help—primarily because of centuries of both stigma and discrimination against persons with mental illness.

The onset of mental illness usually comes as a surprise, and often a shock, not only to those who become ill, but also to their families and other loved ones, who simply do not know what to do or where to go for information or how to seek help. That's why NAMI exists today!

NAMI--National Alliance on Mental Illness--is the largest advocacy organization in the country for those living with a mental illness. It began in the 1970's as a grassroots organization with a small group of mothers who got together to help each other adjust to the challenges of caring for their adult children with mental illnesses. Today, NAMI is a respected national organization with more than 1100 affiliates throughout the country!

NAMI Sarasota County is one of the most active affiliates in Florida. Our mission is to provide education, support and advocacy for individuals and families affected by mental illness. The vast majority of our work is done by volunteers. This allows those who need help and support from NAMI to get that help without payment. We believe cost should not be a barrier that interferes with access to education and support from others who have "lived" experiences.

This *Family Guide on Mental Illness* is an example of a free resource for your family. It is intended to provide important information to help you in your research and understanding of mental illness. It will also direct you to other resources, but feel free to contact us personally if you have questions or just need to talk to someone else who has experienced similar issues to yours. You can call us at 941-376-9631 or send an e-mail to info@namisarasotacounty.org. For additional

information about local NAMI activities and programs, please visit our website at www.namisarasotacounty.org or stop by our Facebook page at www.facebook.com/NamiSarasotacounty.org

We hope the information and references in this Family Guide are useful to you and provide you with additional knowledge about mental illness. Please keep in mind that mental illnesses are biological brain disorders and NOT the fault of the person with mental illness or the family. They are just illnesses, and people with these illnesses deserve our help and care as do people with other physical illnesses.

The definitions and summaries in this *Family Guide on Mental Illness* come from a variety of research reports and published resources. In addition, dozens of professionals, community providers, individuals with mental illness and members of their families have contributed to its development and editing. We know you will find the following information and resources helpful in your search for support.

With Kind Regards,

The Board of Directors
NAMI Sarasota County Florida, Inc.

SPECIAL THANKS

We would like to thank NAMI Pinellas County for granting permission to adapt and reproduce the second edition of the Family Guide on Mental Illness.

We also thank our **Community Partners** whose considerable support of NAMI programs and services help sustain our local organization:

The Green Family Foundation
Community Foundation of Sarasota County - Arthur T. Esslinger Memorial Fund
Vincent Academy



WHAT IS NAMI?

NAMI is the nation's voice on mental illness. Mental illness affects one in every five families. These families go to NAMI—National Alliance on Mental Illness—to help them cope with the challenges they face.

NAMI Pinellas helps individuals with mental illness and their loved ones by focusing efforts in three primary areas that offer hope, recovery, and health to our community through support, education, and advocacy.

NAMI SARASOTA COUNTY SERVICES

SUPPORT:

- NAMI Family Support Group – meets monthly in Sarasota, Venice and North Port
- NAMI Connection Consumer Support Group – meets twice monthly in Sarasota
- NAMI Help Line [941] 376-9631 or e-mail info@namisarasotacounty.org
- NAMI Sarasota County website: www.naimsarasotacounty.org

ADVOCACY:

- NAMI provides a collective voice for persons living with mental illness and their families regarding legislative issues, services, treatment and funding.
- It is through the awareness, education, and support that NAMI is able to work toward the improvement of the lives of those with mental illness and their families, while working to remove the negative stigma communities and society have regularly associated with mental illness.

EDUCATION:

- Family-to-Family: 12-week course taught by nationally trained family members for family, friends and caregivers of individuals with mental illness to assist them in coping and problem solving.
- Peer-to-Peer: 10-week course taught by nationally trained peers to teach those suffering with psychiatric disorders about their illnesses, diagnoses, symptom management, relapse prevention, and coping skills.
- CIT (Crisis Intervention Team) Training: 40-hour program for law enforcement officers on how to calm, assess and facilitate crisis situations, reducing the use of force while enhancing officer safety. As of 2015, 405 Sarasota County law enforcement, correction deputies and officers are actively trained and available for response.

COMMUNITY PRESENTATIONS:

- Education Meetings: Speakers offer community resources and discuss issues related to mental illness -- held monthly for the general public. (see website calendar)
- Speakers Bureau: Presentations about NAMI services, mental illnesses, and coping skills.

RESOURCES:

- NAMI Sarasota County website: www.namisarasotacounty.org
- NAMI National website: www.nami.org NAMI Florida website: www.namiflorida.org
- NAMI Facebook page: www.facebook.com/NamiSarasotacounty.org
- Family Guide on Mental Illness—definitions/explanations/resources/information about mental illness

NAMI SARASOTA COUNTY FLORIDA, INC.

PROGRAMS AND SERVICES

NAMI is a non-profit, grass-roots organization of individuals living with mental illness, their families and friends who are dedicated to improving the quality of life of those affected by mental illness. NAMI is the nation's largest grass-roots advocacy organization representing individuals living with mental illness. NAMI has become the nation's voice on mental illness with affiliates in every state and more than 1100 communities.

INFORMATION AND REFERRAL SERVICES:

The NAMI Sarasota County Helpline receives hundreds of calls each year from individuals living with mental illness, their family members and friends, and healthcare professionals seeking help and information. Many of those who call report that this is the first contact they have made to try to discover what they should do and where they can go for help and information. Others call in frustration when they are unable to find assistance or get help from any other source.

Those who answer the NAMI Sarasota County Helpline have invaluable first-hand information, because they are either living with mental illness--with their own diagnosis or because a family member has a mental illness. Our Helpline team members have the ability to listen confidentially to concerns and then provide information on options. It is not unusual to get calls from individuals working to avoid a crisis from parents or family.

FAMILY-TO-FAMILY EDUCATION COURSE

This is a free, 12-session course for families and friends of individuals with serious mental illnesses. Taught by trained NAMI family members, the participants receive updated information about illnesses of the brain and treatment options, coping skills, and the power of advocacy. Those who take the

NAMI course are better equipped to work with their family member or friend and the mental health system in seeking and obtaining help.

PEER-TO-PEER EDUCATION COURSE

This is a 10-session education course on recovery for any person with a serious mental illness. Like Family-to-Family, the course is free and is taught by a team of three trained peer mentors who are experienced at living with their own mental illnesses. Participants learn about serious mental illnesses, coping skills, empowerment and advocacy.

NAMI FAMILY SUPPORT GROUP

This NAMI support group is facilitated by family members for other families and loved ones to give them support and feedback on their daily challenges and special issues they face. Groups are confidential gatherings of caregivers who need a haven of understanding based on lived experience with mental illnesses among their family and friends.

NAMI CONNECTION SUPPORT GROUP

Individuals living with mental illnesses need support regularly to be able to share information confidentially about their personal roads to recovery, as well as the special challenges they face coping with their illnesses. This group is led by specially trained persons who are in a unique position to offer support

and empathy from people who know what it's like and who have "been there."

GENERAL EDUCATION

At monthly Education Meetings, experts from the community speak on a wide-range of mental health, legal, care giving and life management topics.

ADVOCACY AND CONSULTATION: NAMI is directly involved in advocacy for the needs of those with a mental illness and their families. Volunteers serve on local committees and coalitions and participate extensively with agencies that address mental health and substance abuse issues. Members are trained on how to provide information to their local, state and federal elected officials.

PUBLIC RESOURCES: As a part of its work in advocacy, NAMI provides communication and information through a number of resources which include NAMI websites www.nami-pinellas.org and www.nami.org, as well as newsletters, brochures, public testimony, media response and appropriate visibility in many other settings. NAMI also is available as a resource to the media on issues concerning mental illness and its effect on communities, families, and individual lives.

CRIMINAL AND JUVENILE JUSTICE ISSUES

The state's jails and prisons often become the default housing for individuals with a mental illness who have experienced a public mental health crisis that results in incarceration. Statistics indicate that a majority of the people in jails and prisons who have a severe

mental illness may be better served in another setting. NAMI is encouraging and supporting training and programs to assist law enforcement throughout the state to identify and properly refer these individuals. Law enforcement officers are often the first responders to come in contact with a crisis event; thus, NAMI strongly supports Crisis Intervention Team (CIT) training, an education program that provides 40 hours of specialized training for law enforcement officers, teaching them how to respond to calls concerning persons with a mental illness in crisis. In this course, officers are exposed to basic dynamics of common types of mental illnesses and to the viewpoints and feelings of mental health consumers first hand. They become skilled in de-escalating potentially volatile situations, gathering relevant information and evaluating the individual's social support system and therefore are more appropriately placed for assistance.

OUR VOLUNTEERS

NAMI volunteers are advocates who work to reduce stigma and discrimination and are an extremely valuable source of help and support. They lead all of our NAMI signature, best practices education courses and support groups and dedicate hundreds of hours a year to enrich the lives of Sarasota County residents who are affected by mental illness.

For more information about NAMI Sarasota County programs and services, please contact us directly:

NAMI Warm Line: 941-376-9361
info@namisarasotacounty.org
namisarasotacounty.org

SEVERE MENTAL ILLNESS and SUBSTANCE ABUSE

SYMPTOMS OF MENTAL ILLNESSES

Mental illness refers to a group of brain disorders that can profoundly disrupt a person's ability to think, feel, and relate to others and their environment. Often this results in an inability to cope with the ordinary demands of life. Symptoms vary and every individual is unique. All persons with mental illness typically have some of the characteristics summarized below. While a single symptom or isolated event is not necessarily a sign of mental illness, professional help should be sought if symptoms persist or increase.

Psychotic Diagnoses for both Adults and Children are based upon the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*- known as DSM-5. It is published by the American Psychiatric Association (APA).

The mission of the American Psychiatric Association is to:

- Promote the highest quality of care for individuals with mental disorders (including intellectual disabilities and substance use disorders) and their families;
- Promote psychiatric education and research; advance and represent the profession of psychiatry.

Behavior

A variety of symptoms characterize some of the ways mental illness can affect a person's behavior:

- hyperactivity, or inactivity, or alternating between the two
- deterioration in personal hygiene
- noticeable and rapid weight loss
- drug or alcohol abuse
- forgetfulness and loss of valuable possessions
- attempts to escape through geographic change, frequent moves or hitchhiking trips
- bizarre behavior (staring, strange posturing)
- unusual sensitivity to noise, light, and clothing
- social withdrawal.

Often, the symptoms of mental illness are cyclical, varying in severity from time to time. The duration of an episode also varies. Some persons are affected for a few weeks or months; for others, the illness may last many years or a lifetime. There is no reliable way to predict the course of the illness.

Thought Disorders

Thought Disorders are characterized by the inability to concentrate or cope with minor problems, irrational statements, peculiar use of words or language structure, excessive fears, or suspiciousness.

Expressions of Feelings

The way persons with mental illness express their feelings can be characterized by changes such as hostility from someone who formerly was passive and compliant, indifference (even in highly important situations), inability to cry or excessive crying, inability to express joy, and inappropriate laughter.

DIAGNOSIS OF MENTAL ILLNESSES

Accurate diagnosis may take time. The initial diagnosis is often modified later, perhaps several times, because it takes some time to evaluate response to treatment. It also can be difficult to pinpoint the problem because the individual has more than one disorder; for example, schizophrenia with an affective disorder, or an anxiety disorder such as obsessive-compulsive disorder with schizophrenia, or a personality disorder. It is important for the psychiatrist to reevaluate the diagnosis periodically in order to work out the best treatment approach. In many cases of apparent mental illness, alcohol, or drug abuse, or an underlying medical disease such as hypothyroidism, multiple sclerosis or brain tumor is found to be the problem. A thorough physical examination should be the first step when mental illness is suspected.

KINDS OF MENTAL ILLNESS

Depression

The following characteristics typically are included in a description of depression:

- Sudden onset of sadness unrelated to events or circumstances
- Loss of interest in once pleasurable activities
- expressions of hopelessness
- excessive fatigue and sleepiness or an inability to sleep
- feelings of worthlessness or guilt
- frequent tearfulness
- pessimism
- perceiving the world as dead
- thinking or talking about suicide.

Schizophrenia

The term schizophrenia comes from the Greek terms meaning “splitting of the mind.” People with schizophrenia do not, however, have a “split personality.” They have a disorder that affects their thinking and judgment, sensory perception, and their ability to interpret and respond to situations or stimuli appropriately. There are usually drastic changes in behavior and personality. Lack of insight about the illness is one of the most difficult symptoms to treat, and it may persist even when other symptoms (such as hallucinations and delusions) respond to treatment.

Schizophrenia will affect about 1% to 2% of the U.S. population at some time during their lifetime. It is usually first diagnosed between the ages of 17 and 25. There may be several psychotic episodes before a definitive diagnosis is reached. When this illness first appears, the person could feel tense and have difficulty concentrating. He/she might start to withdraw; school or work performance may begin to deteriorate; general

appearance and personal hygiene could deteriorate; friends often drift away. Parents often think this is just adolescent behavior gone astray, and even doctors may be uncertain about a diagnosis in the early stages.

Signs & Symptoms of Schizophrenia

Alteration of the senses: The senses (sight, hearing, touch and/or smell) may be intensified, especially early in the disease.

Inability to process information and respond appropriately (also known as “thought disorder”): Because the individual has difficulty processing external sights and sounds, and because he/she experiences internal stimuli that others are not aware of, his/her response is often illogical or inappropriate. Thought patterns are characterized by faulty logic, disorganized or incoherent speech, blocking, and sometimes neologisms (made-up words). He/she may relate experiences and concepts in a way that seems illogical to others, but which holds great meaning and significance for them.

Delusions: These are false ideas that the person believes to be true. The individual adheres to these ideas in the face of reason. Some persons develop excessive religious preoccupation; however, unusual beliefs may be the product of a person’s culture and can only be evaluated in this context. There are common kinds of delusions, such as paranoid delusions, which are characterized by the belief that one is being watched, controlled, or persecuted. Individuals also experience grandiose delusions, which are centered on the belief that one has vast wealth, special powers or is a famous person, such as a politician or religious leader.

Hallucinations: Hallucinations are sensory perceptions with no external stimuli. The most common hallucinations are auditory, hearing “voices,” which the person may be unable to distinguish from the voices of real people. Delusions and hallucinations are the result of over-acuteness of the senses and an inability to synthesize and respond appropriately to stimuli. To the person experiencing them, however, they are real. Medications can be very helpful in controlling hallucinations.

Change in emotions: Early in the illness, the person may feel widely varying, rapidly fluctuating emotions and exaggerated feelings, particularly guilt and fear. Emotions are often inappropriate to the situation. Later there may be apathy, lack of drive, and loss of interest in and ability to enjoy activities.

Changes in behavior: Slowness of movement, inactivity, and withdrawing from social situations are common changes that can occur in a person’s behavior. Motor abnormalities such as grimacing, posturing, odd mannerisms, or ritualistic behavior are sometimes present. There also could be pacing, rocking, or apathetic immobility.

There is no cure for schizophrenia, but there are many medications available which can reduce the symptoms. Finding the right medication therapy is a very complex process that demands a working relationship with a psychiatrist that is based on trust. The outcome is very successful when the individual is treated appropriately with medications, has access to rehabilitation services, and has a supportive living environment.

Mood Disorders

Mood disorders or affective disorders include major depression and bipolar disorder and are some of the most common psychiatric diagnoses. The terms ‘mood’

and ‘affective’ refer to the state of one’s emotions. A mood disorder is marked by periods of extreme sadness or excitement, or both. If untreated, these episodes tend to recur or persist throughout life. Even when treated, there could be many repeat episodes.

Depression

Depression in some degree will affect between 10% and 20% of the population at some time during their lives, some as often as once or twice a year, with episodes that may last longer than six months each.

Beyond a persistent sad mood, the symptoms of depression include:

- Loss of interest in daily activities, loss of energy and excessive tiredness
- Poor appetite and weight loss, or the opposite, increased appetite and weight gain
- Poor concentration
- Sleep disturbance--sleeping too little or sleeping too much in an irregular pattern
- Feelings of worthlessness or guilt that can reach unreasonable proportions
- Feelings of hopelessness about the future
- Recurrent thoughts of death or self-harm, wishing to be dead or attempting suicide.

People with the most severe depression find they cannot work or participate in daily activities, and often feel that death would be preferable to a life of such pain. Probably more than with any other illness, people with depression are blamed for their problems and told to “snap out of it,” “pull themselves together,” etc. Often, others will say a person “has no right” to be depressed. It is critical for family and friends to understand that depression is a serious illness. The person with this illness can’t ‘snap out of it’ any more than a person with diabetes can will away that illness.

Depression is a very treatable illness. Approximately 75% of people properly diagnosed respond to treatment.

Bipolar Disorder

Bipolar disorder is characterized by extreme shifts in mood, energy and functioning. These shifts fluctuate between periods of depression and an extremely elevated state known as mania.

Symptoms of hypomania or the more severe state of mania include:

- Euphoric, expansive mood
- Boundless energy, enthusiasm, and activity
- Decreased need for sleep
- Rapid, loud, disorganized speech
- Short temper, argumentative, or irritable mood
- Delusional thinking.
- Activities that have painful consequences such as spending sprees, reckless driving, or increased sexual behavior.

Bipolar may appear in childhood or adolescence, although the majority of cases appear in young adulthood. Many believe there is a genetic component to the illness, since bipolar illness and major depression often run in families.

Other Disorders

Anxiety Disorders include Generalized Anxiety Disorder, phobias, panic disorder, obsessive-compulsive disorder (OCD), and post-traumatic stress disorder (PTSD). Symptoms can be so severe that they can become disabling, but these illnesses seldom involve psychosis.

Panic Disorder: Panic attacks come “out of the blue” when there is no reason to be afraid. Symptoms may include sweating, shortness of breath, heart palpitations, choking, or faintness.

Ironically, some of the symptoms of mania lead affected people to believe they are not experiencing manic symptoms and have never felt better. The euphoric mood may continue even in the face of sad or tragic situations. Even when the person continues to feel swept up in the mood of excitement, family and friends may notice serious problems. For example, people with mania often go on spending sprees, become promiscuous, or abuse drugs and alcohol while being unaware of the serious consequences of their behavior.

Fortunately, bipolar disorder is one of the most treatable illnesses, generally with some of the newer atypical medications. In addition to medications, many people with bipolar disorder find individual behavior modification therapy and peer support groups helpful. Many of the symptoms of mania also can occur in schizophrenia, which could complicate a diagnosis.

Both depression and bipolar disorder are highly correlated with suicide and suicide attempts.

Schizoaffective Disorder

This illness is a combination of psychotic symptoms such as hallucinations or delusions and significant mood symptoms, either depression or mania or both. The psychotic symptoms persist when the mood symptoms resolve.

Obsessive-Compulsive Disorder: OCD can cause the individual to have only obsessions or only compulsions, but most people have both. Obsessions are repeated, intrusive, unwanted thoughts that cause extreme anxiety. Compulsions are excessive ritual behaviors that a person uses to diminish anxiety. Some examples of this are hand washing, counting, repeated checking, and repeating a word or action. Treatment includes both medication and therapy.

Post-Traumatic Stress Disorder (PTSD): according to the DSM-IV-TR, PTSD is the development of characteristic symptoms following exposure to an extreme traumatic stressor which caused intense fear, helplessness, or horror. Stressors can include combat, abuse, assault, or severe accidents. Symptoms can include repeatedly experiencing the event, as well as persistently avoiding stimuli that reminds the person of the event. Hallucinations and paranoia can occur in some severe cases. PTSD is associated with increased rates of depression, substance-related disorders, and panic disorder.

Substance Use Disorders

Substance Use Disorders include abuse and dependence on mind altering substance.

Substance Abuse is defined as repeated use of substances despite adverse social consequences, such as failure to meet family, school, or work responsibilities; interpersonal conflicts; legal problems; or using substances in potentially dangerous situations.

Substance Dependence, commonly known as addiction, is characterized by the presence of several physical and behavioral symptoms. One of these symptoms is the need for increased amounts of substances to achieve the desired effects, which is known as tolerance. Individuals also can experience withdrawal symptoms when they stop using.

These individuals typically devote increasing amounts of time and resources obtaining and using drugs or alcohol, and can give up other interests and responsibilities. People who are addicted might try unsuccessfully to control their use, take more of a substance or use it more often than they plan to. Many also continue to use despite knowledge of related health problems.

Substance dependence can appear without previous substance abuse, while some people meet criteria for substance abuse without ever becoming dependent. However, studies tend to indicate a better-than-average chance that substance abusers will become addicted.

In the past, many thought substance use disorders were caused by moral failings or a lack of willpower. However, research indicates that there are identifiable genetic, psychological, and social risk factors that make some people more vulnerable to abuse or dependence. Over time, substance dependence appears to lead to changes in the brain that create a continued risk of relapse despite a person's sincere desire for sobriety. Substance dependence is now

generally considered to be a chronic condition. A relapse is not a sign of failure but rather, a possibility--just as with heart disease or diabetes.

Each person should develop a plan in advance for returning to recovery as quickly as possible. Relapse can provide him/her and family, concerned friends, and professionals with useful information to help strengthen the individual's recovery support system.

Co-occurring Disorders

It is estimated that about a third of adults with mental health diagnoses have a co-occurring substance use disorder, while more than half of adults with substance use disorders have co-occurring mental health disorders. Symptoms of mental health and substance use disorders often interact to precipitate, mimic, mask, or worsen each other. Co-occurring disorders tend to interact in ways that negatively affect a person's ability for self-care and successful functioning.

Accurate assessment and treatment designed to address co-occurring disorders offer the best opportunity for recovery. According to the SAMHSA National Survey on Drug Use and Health (2010), 9.2 million adults had both serious psychological distress and a substance use disorder; and of that number, 55.6% received no treatment. Of the 44.4% who did get treatment, 33.6% received only mental health care, and 3.1% only substance abuse services. Only 7.7% received specific co-occurring treatment.

Without an integrated system of care, people with co-occurring disorders may receive "parallel" or "sequential" treatment, moving between mental health and substance abuse treatment providers depending on which disorder is more acute at the time. Professionals, as well as concerned family members or friends, may not get a complete understanding of the person's individual needs.

People with co-occurring disorders benefit most from treatment methods that have the flexibility to address both disorders. Continuity of care and a full range of services including psychiatric, social, recreational, vocational, and cultural needs are important components of treatment. It also is important that treatment includes specialized counseling to address life skills, relapse prevention, and any trauma or abuse issues. Recovery support groups such as "Double Trouble" that welcome persons with co-occurring disorders also are helpful.

Suicide

Suicide may be a manifestation of mental illness, but not all persons who commit suicide are mentally ill.

Signs of depression and warning signals of suicidal thoughts can include:

- **Change in personality:** Usually sad, withdrawn, irritable, anxious, tired, indecisive, apathetic, or moody
- **Change in behavior:** Difficulty concentrating on school, work or routine tasks; change in eating habits such as a loss of appetite and/or weight, or conversely, overeating and/or weight gain, excessive tearfulness or crying
- **Change in sleep patterns:** Oversleeping or conversely insomnia, sometimes with early waking
- **Loss of interest:** Reduced interest in friends, sex, hobbies, or other activities previously enjoyed
- **Fear of losing control:** Fear of “going crazy” or harming oneself or others
- **Worries about money or illness:** Either real or imagined
- **Feelings of helplessness and worthlessness, overwhelming guilt, shame or self-hatred.**
- **Sense of hopelessness about the future**
- **Drug or alcohol abuse:** It should be noted that drug and alcohol abuse lowers inhibitions and that people tend to do things when they are drunk or high that they wouldn't do normally if they were sober.
- **Recent loss:** Loss through death, divorce, separation or a broken relationship, even the loss of a job, money, or status, may trigger suicidal thoughts
- **Loss of religious faith**
- **Nightmares**
- **Agitation, hypertension, and restlessness** may indicate masked depression
- **Giving away possessions**

Do not be afraid to ask the person showing such symptoms if he or she is thinking about suicide. Just about everyone has contemplated suicide, however fleetingly, at one time or another. Raising the question of suicide shows you are taking the person seriously and responding to the potential of his or her distress.

If the answer is “Yes, I do think of suicide,” you must take it seriously. Ask questions like: Have you thought about how you would do it? Do you have the means? Have you decided when you'll do it? Have you ever tried suicide before? What happened then?

Depending on their response, do not hesitate to contact your local 24-hour mental health crisis service, or your emergency 9-1-1 telephone service for help.

OTHER RESOURCES FOR THOSE CONCERNED ABOUT SUICIDE

NAMI refers you to the following websites for more in depth information on this topic:

www.nami.org • www.floridasuicideprevention.org

SERIOUS DISORDERS OF CHILDREN & ADOLESCENTS

Some psychiatric disorders such as autism spectrum disorder typically start in childhood, while others such as mood disorders may first be diagnosed during adolescence or adulthood. Although there is still much to learn about childhood disorders, it is generally accepted that many, if not most, of the disorders listed below are primarily biological in nature, that is, based on structural and /or chemical abnormalities in the brain. They are sometimes referred to as neurological disorders.

Autism and other pervasive developmental disorders, schizophrenia, and schizoaffective disorder are clearly biologically based, resulting from a malfunction of the brain. Other disorders, including attention deficit hyperactivity disorder (ADHD), anxiety disorder, and mood disorders can also be primarily biologically based and generally respond to drug therapy. For neurobiological disorders, appropriate medical diagnosis and treatment are essential. If a child cannot process information or is not in control of his emotions, psychosocial and educational strategies alone are not likely to be effective.

Many professionals continue to be reluctant to “label” children with a mental illness diagnosis given the uncertainties about behavior that may be due to developmental problems, the impact of illegal drugs or alcohol, and the ordinary emotional turmoil that accompanies the passage from adolescence to adulthood. However, families need to know what is wrong with their child. A diagnosis is essential to the task of designating an effective treatment and educational approach.

Autism Spectrum Disorder

Autism Spectrum Disorder is characterized by deficits in social communication, social interaction, and emotional associations. It can be observed in multiple areas of life inclusive of, but not limited to, impaired relationship development and maintaining a relationship, restricted behavioral patterns and ritual like patterns. Intellectual disability and autism spectrum occur very often together.

Anxiety Disorder

Anxiety may or may not be associated with a specific situation. Anxiety and worry may be far out of proportion to the actual likelihood or impact of a featured event. Anxiety disorders include panic attacks, social phobia, obsessive-compulsive disorder, and post-traumatic stress disorder.

Bipolar Disorders & Depression

In children, aggressive or hostile behaviors may mask underlying depression. Parents should consider the possibility of depression when there are unexplained physical complaints, a drop in school performance, social withdrawal, apathy, increased irritability, tearfulness, sleep problems, appetite changes, and suicidal behavior or symptoms. Children with bipolar disorder may present with mood swings, unpredictable angry outbursts, increased activity or irritability.

Schizophrenia

Schizophrenia usually starts in the late teens or 20's, and seldom occurs before adolescence, but some cases at age five or six have been reported. There is evidence, however, that certain structural changes in

the brain are present at birth in individuals who later develop schizophrenia. The essential features are the same for children and adults; however, it may be difficult to diagnose in children.

Tourette's Disorder

Tourette's Disorder often begins when a child, age five to seven, begins to have tics such as eye blinking, grimacing, or shoulder jerks. Sudden vocalizations (barks, clicks, yelps) may appear later, and still later the person may involuntarily say words or phrases. Uttering obscene words out of context occurs in less than 10% of patients.

ADHD--Attention Deficit Hyperactivity Disorder

One of the many prevalent and serious disorders affecting children and adolescents is Attention Deficit Hyperactivity Disorder. ADHD has serious impact on the lives of many children and adolescents, and is frequently misunderstood.

ADHD is generally categorized into four sub-groups. The first two-groups reflect the major characteristics associated with ADHD: inattention, high activity level, and impulsivity. The first group is where the primary characteristics are inattentiveness and disorganization. This is called ADHA, predominantly inattentive type. The second condition is where hyperactivity and impulsivity are the striking features. This is called ADHD, predominantly hyperactive-impulsive type. The third condition is a combination of the first two while the fourth is considered ADHD, not otherwise specified.

The U.S. Department of Education uses the term ADD (Attention Deficit Disorder) for the type of ADHD characterized by inattentiveness and disorganization and reserves the term ADHD for the type in which hyperactivity and impulsivity predominate.

ADHD is a complex neurobiological disorder and researchers believe that chemicals in the brain that are not working properly cause the symptoms of ADHD. More specifically, it is believed that the neurotransmitters, the chemical messengers of the brain, do not work properly in individuals with ADHD. As a result, many children with ADHD have difficulties in several spheres of functioning that may cause significant problems at home, at school, and in the community. Although children may be inattentive and impulsive at times, youngsters with ADHD behave this way more frequently and are more likely to cause problems at home and at school.

For the diagnosis of ADHD to be given, the symptoms need to have been present before the age of seven, and there must be impairment in two or more settings (such as home and school). It is often the case that diagnosis is first made after children start school, and begin to underachieve academically. While ADHD is typically thought of as a disorder of young children, in fact it frequently continues into adolescence and often into adulthood. Researchers have estimated that ADHD affects three to five percent of all children. ADHD is anywhere from three to six times more common in boys than girls.

ADHD often occurs with other conditions. According to information from a major study at the National Institute of Mental Health, two-thirds of children with ADHD have at least one other coexisting condition. Some of the most common co-occurring conditions are oppositional defiant disorder, anxiety, learning disabilities, and depression.

Common Features of Children & Adolescents with ADHD: One of the primary complaints from parents and teachers is that children and adolescents with ADHD have difficulty following rules and

instructions. The two core characteristics of ADD, inattention and impulsivity, are largely to blame. Parents often complain that their child doesn't complete his chores. He/she may start a job but somehow never gets it finished.

Impulsivity is the second primary characteristic of ADD. Specific examples include: responds quickly without waiting for instructions, makes careless errors, doesn't consider consequences, takes risks, carelessly damages possessions, has difficulty delaying gratification, and takes short cuts in work.

Both inattention and impulsivity contribute to disorganization, difficulty getting started, and failure to complete homework. As a result, children with ADHD may have lower self-esteem as early as first or second grade. Many children with ADD are less mature and may be developmentally behind their peers by as much as three or four years.

One way of characterizing the deficiencies of many children with ADHD is to indicate that they have "executive functioning" difficulties. Deficits in key executive function skills that interfere with the ability to do well academically include such things as: holding facts in your head and manipulating them, getting started on tasks, staying alert, and finishing work.

The challenges facing teenagers and ADD are more complex. The risk of school failure, school suspension or expulsion, dropping out of school, substance abuse, pregnancy, speeding tickets, car wrecks, and suicide are greater for them.

Parents have observed that teenagers with ADHD are more difficult to discipline. On a more positive note, children with ADHD can be very engaging, enthusiastic, and certainly energetic.

Parents who think their child may be exhibiting behavior reflective of ADHD should seek the opinion of a mental health professional or pediatrician who specializes in ADHD. Parents should gather information from the school about the child's behavior. A diagnosis should be based upon a comprehensive evaluation, including interviews, tests, questionnaires, and direct observation. Interventions typically include psychosocial and behavioral components as well as medication.

Parents with children with ADHD can find support groups to be an invaluable aid. In addition to parent organizations that deal with a variety of mental disorders such as the National Alliance on Mental Illness, and the Federation of Families for Children's Mental Health, parents can contact CHADD (Children and Adults with Attention Deficit Disorder).

It is important to keep in mind that ADHD is not just a passing phase for children. It is a long-term, sometimes life-long condition. Many children receive effective intervention and family support, make great progress, and learn how to put their attributes to best use, especially in their adult years. Without effective intervention and family support, however, ADHD can significantly impair functioning for many years and help bring on other serious emotional and behavioral conditions.

Summarized from an article by Dan Casseday and Bob Friedman, University of South Florida.

SUBSTANCE USE DISORDERS

According to the 2011 Monitoring the Future study, half of all adolescents have used illicit drugs by 12th grade, and 70% have tried alcohol. While national trends show an overall decline in adolescent substance use, the rates of new users of prescription opiates, which are perceived by most teens as less

harmful and are readily available, are now comparable to the rates of new users of marijuana. The National Survey on Drug Use and Health reports that ages 14-17, the high school years, are still the highest risk time for starting to use of alcohol and drugs. The most commonly abused substances for teens are alcohol and marijuana, but in recent years, more youths initiated non-medical use of prescription drugs than started using marijuana.

Most adolescents engage in either experimental or social use; that is, using substances out of curiosity, or to be part of the crowd. However, research indicates that by age 18, about one in four adolescents will meet criteria for substance abuse, and one in 5 for substance dependence (see page 10 for a more detailed description of the differences between substance abuse and dependence).

Sometimes parents may minimize the behavior, particularly with alcohol or marijuana, or may rationalize that “All kids try it, so did I.” However, recent research suggests that alcohol has a significantly greater impact on learning and memory in adolescents than adults, but that adolescents experience less sedation and motor coordination effects so may not accurately perceive their levels of impairment. The common adolescent pattern of binge drinking followed by withdrawal seems to carry a higher risk of long-term impairment in memory, cognitive functioning, and attention, which are essential for successful development to adulthood.

It can be difficult for parents to distinguish between experimental use and abuse. The best indicator is observing how much the substance use is affecting the teen’s life, including academic achievement, physical health, social activities, and choice of friends. A substance abuse evaluation, including drug testing, can help determine whether or not treatment is

necessary. Many adolescents do not see their substance use as a problem; most teens enter treatment because of juvenile justice mandates.

Family therapy appears to be an important component of successful treatment for teens. However, in some cases families are not willing to participate, or family members may use substances themselves, and adolescents rarely have the options adults do to leave environments that put their recovery at risk. Teens also may feel uncomfortable in traditional 12-step programs due to age differences or difficulty speaking up in groups. Youth who are in the process of discovering their identity may resist what they see as pressure to label themselves as alcoholics or addicts

Co-Occurring Disorders

Data from the Substance Abuse and Mental Health Services Administration and the U.S. Department of Health and Human Services indicates that almost half of youths with a mental health diagnosis have a co-occurring substance use disorder, while about 21% of youths admitted to substance abuse treatment have a co-occurring mental health disorder. The most common diagnosis is conduct disorder, followed by mood disorders. Research also supports an association between post-traumatic stress disorder and substance use disorders, especially for girls.

“Internalizing” mental health disorders such as anxiety or depression seem somewhat more likely to precede substance abuse, while “externalizing” disorders, i.e., conduct disorder or oppositional defiant disorder, may start simultaneously with substance use. Co-occurring disorders also seem to correlate with a higher risk of relapse within the first six months after treatment.

Just as with adults, adolescents may experience parallel or sequential rather than integrated treatment,

shifting between the substance abuse and mental health service systems depending on which disorder is most acute at any given time.

Adolescents also face other challenges in getting appropriate help for co-occurring disorders, including the lack of research about psychiatric medications and teens, and the importance of finding treatment

that is tailored to the youth's developmental stage. These adolescents often are involved with many other systems and need case management to reduce conflicts and promote effective cooperation.

SEEKING TREATMENT

It is important to know that the most expensive care is not necessarily the best. Private care is not necessarily better than the care offered through your local community mental health service program. In fact, care through the public sector may be necessary before certain community services are accessible.

Suggestions for seeking treatment:

- **Most important, understand it is neither your fault nor the fault of the person in crisis.**
- **Be informed as to what resources are available:** Contact your local community mental health services program or NAMI Pinellas for referral information.
- **Evaluate the situation:** If you think there is danger to any person, **call 9-1-1** or law enforcement. If a crisis occurs, but there appears to be no immediate risk, take the individual to a psychiatric emergency service or call the crisis intervention officer, if available.
- **If the need is not urgent; take time to talk with your relative.** Do not make a diagnosis but stress that you care and are concerned and offer your help. Ask them how they feel and how they feel about talking with a doctor or therapist. Be honest and direct. Use terms that you believe are most acceptable to them (e.g.,

unhappy, nervous, mixed up, worried). Respect their right to choose. Understand that they may need to deny what is happening at first, but by discussing it with them you have "opened the door," and they may later be ready to talk and/or seek help.

- **Understand their fears:** Be patient and supportive. Accept that they may be more willing to talk with a trusted friend, doctor, clergy, or another family member.
- **Always be honest:** It is very important that trust exists if you are able to help your friend or relative. It will not help them to argue or deny that what they are seeing, hearing and feeling is real. Assure them that you love them and understand that what they are experiencing is real to them and that you want to help. Do not hide your concern. Do not whisper.
- **Share your concerns:** You should always share your concerns with family members and try to get their cooperation.

However, if their condition deteriorates, if you have serious concerns about their wellbeing, and you believe a crisis is imminent, you may need to pursue an involuntary order for treatment, also known in Florida as The Baker Act.

MEDICATIONS

Keep in mind as you read this section that new and better medications are being tested and released every day. It is in both families' and consumers' best interest to keep up to date in this area. Read, explore, listen, and discuss with the appropriate physician. One of the best sources of information on medications, as well as other areas of treatment, is the national NAMI website, www.nami.org.

Psychotropic medications are often very useful in helping the person with mental illness to think more clearly and to gain control of his or her own thoughts, actions, and emotions. Medications also can dramatically decrease the need for hospitalization and increase the person's ability to benefit from rehabilitation programs and to function independently. Any licensed Physician (MD or DO), Psychiatrist or Nurse Practitioner may prescribe medications. However, a Psychiatrist and a Psychiatric Nurse Practitioner are more knowledgeable on psychotropic medications and should supervise and determine the need for ongoing drug therapy.

It is important to know the names of the prescription medications, their dosage, therapeutic benefits, and any side effects observed, and risks or precautions. Medications produce both beneficial effects and side effects.

People are highly variable in regard to how much benefit they will get from a drug and the type and severity of the side effects they will experience. While side effects may be evident soon after starting to take

the medication, the desired effect may not be seen for several weeks. In fact, it may take months of continuous use before the maximum benefit is evident. Some side effects, especially those that appear early, are temporary and may go away or become less severe after a few weeks.

Resistance to taking prescribed medications is often due to unpleasant side effects. It is important that the prescribing physician discusses this with the patient and seeks the most effective and acceptable plan for treatment. The individual will be given an explanation and written summary of the most common side effects of medications which have been prescribed.

There are four main groups of drugs used to treat the symptoms of mental illness: mood stabilizers, antidepressants, anti-anxiety drugs and anti-psychotics.

1. Mood Stabilizers: There are several medications used to reduce wide mood swings of persons, especially with bipolar illness. Some of these medications require monitoring, so that symptoms can be controlled with the fewest side effects.

2. Antidepressants: This group of medications is used to treat severe depression. Some common examples include:

- Celexa
- Effexor
- Elavil
- Lexapro
- Paxil
- Prozac
- Remeron
- Zoloft
- Wellbutrin.

3. Anti-Anxiety Agents: A number of medications can be used to reduce anxiety, relax muscles, and calm the individual. They should generally be used only for short periods of time. Some are addictive and may produce severe reactions if used with alcohol.

4. Anti-psychotics: These medications are most commonly used for treatment of the symptoms of psychosis, which include unusual or bizarre behavior, hallucinations, delusions, agitation, and disturbed thought processes. Some anti-psychotics are now used as mood stabilizers to lessen the mood swings that occur with Bipolar Disorder. They are sometimes used to calm the severely hyperactive behavior seen in the manic phase of bipolar disorder. They also can help prevent relapse and/or hospitalization.

Some of the more common anti-psychotic medications include:

- Abilify (aripiprazole)
- Clozaril (clozapine)
- Fanapt (iloperidone)
- Geodon (ziprasidone)
- Haldol (haloperidol)
- Invega (paliperidone)
- Loxitane (loxipane)
- Mellaril (thioridazine)
- Moban (molindone)
- Navane (thiothixene)
- Prolixin (fluphenazine)
- Risperdal (risperidone)
- Serentil (mesoridazine)
- Seroquel (quetiapine)
- Stelazine (trifluoperazine)
- Thorazine (chlorpromazine)
- Trilafon (perphenazine)
- Zyprexa (olanzapine)

Some significant side effects of this group of drugs are:

- **Allergic Reactions**
- **Autonomic Reactions:** dizziness, dry mouth, blurred vision, and difficulty with urinating and constipation
- **Drowsiness Extra-pyramidal Reactions:** movement problems, tremors
- **Tardive Dyskinesia:** involuntary movements

CAUTION

Optimal use of medications for the treatment of severe mental illnesses restores a quality of life to the individuals affected, as those medications are used in combination with support and behavior modification therapies.

The advice of a physician, particularly a psychiatrist, is advised so that optimal dosage can be achieved as quickly as possible as some of these medications may be addictive if used inappropriately. Please note that oral medications may produce serious reactions if used with alcohol.

It also is important to know that medications should be taken as prescribed. Abruptly discontinuing certain medications can result in serious symptoms that can range from mild to life threatening. In addition, the use of certain medications requires a doctor to order periodic lab work to measure the medication level in the bloodstream. Overall, communication with the physician should be a priority.

For a wealth of information on medications used to treat mental disorders, including a comprehensive list of medications, go to the National Institute of Mental Health website on medications:
www.nimh.nih.gov/health/publications/mental-health-medications/complete-index

Medication PAPs -- Patient Assistance Programs

Pharmaceutical companies may offer free medications for needy patients. Pharmaceutical Research and Manufacturers of America (PhRMA)

often provides free medications to physicians whose patients might not otherwise have access to the needed drug. PhRMA may be reached through its website, www.phrma.org or contact the Partnership for Prescription Assistance at 888-477-2669 or on-line at www.pparx.org/intro/php.

RESOURCES FOR CARE

MENTAL HEALTH PROFESSIONALS

Any of the following may be involved in assessment and planning for treatment and care. Each has a specific task but also is part of the treatment team. Duties and responsibilities will vary.

Psychiatrists are physicians (MD or DO) with specific expertise in psychiatry. Psychiatrists typically have received four years of medical training, and then another four years of specialty training in psychiatry. They assess, make the diagnosis, and prescribe medications and possibly provide other treatment. They work with the treatment team to plan for care in the hospital and after discharge. They may provide individual or group psychotherapy.

Clinical psychologists can be involved in administering diagnostic tests and formulating the diagnosis, and could have other responsibilities similar to those described for psychiatric nurses and social workers.

Advanced Registered Nurse Practitioners--ARNP
In Florida, an Advanced Registered Nurse Practitioner (ARNP) is defined by s. 464.003, Florida Statutes, and According to Rule 64B9-4.010(1), Florida Administrative Code, "An Advanced Registered Nurse Practitioner shall only perform medical acts of diagnosis, treatment, and operation pursuant to a

protocol between the ARNP and a Florida-licensed medical doctor, osteopathic physician, or dentist."

It is a collaborative Practice Agreement. A written protocol signed by all parties, representing the mutual agreement of the physician or dentist and ARNP.

Psychiatric nurses have specific training in psychiatry. They generally have major responsibility for direct care in the hospital, day treatment programs or community mental health centers. They also can conduct individual or group counseling.

Social Workers, Counselors, and Therapists are licensed as Clinical Social Workers, Mental Health Counselors, and Marriage and Family Therapists. They work with the consumer, family and the community in the context of the person's total life situation.

Case Managers coordinate care and services in the community for the individual living with mental illness. They assist in obtaining housing, and linking the person to rehabilitation services and income programs such as SSI and SSDI. They generally work for community mental health centers or an agency under contract with community mental health programs. The term 'case manger' sometimes is used interchangeably with social worker; although,

education, experience, responsibilities and regulatory licensing are different.

COMMUNITY MENTAL HEALTH CENTERS (CMHCs)

Because serious mental illness is likely to require treatment over a long period of time, or an entire lifetime, most persons with such disorders will use the services of their local community mental health center. CMHCs may be involved in the initial assessment. The entry point for services may be by appointment with an intake worker, through crisis or psychiatric emergency services, through the commitment process, or by referral from a jail or homeless shelter.

Once a person is determined to be eligible for services, a case manager may be assigned to assist with linking the individual to such services as crisis intervention, income support, rehabilitation services, counseling services, and/or outreach. CMHCs also can offer residential and vocational services to eligible individuals. In addition, there may be a family education program to provide support and information to family members.

Payment for CMHCs is based on ability to pay. Most CMHCs are Medicaid providers. Many also are funded by the Florida Department of Children and Families through the managing entity--Central Florida Behavioral Health Network.

Inpatient Psychiatric Services

Individuals can receive inpatient treatment at either Crisis Stabilization Units (CSU) or at hospitals that have psychiatric units. A receiving facility means a facility, either private or public, that has been designated by the Department of Children and Families to receive individuals under emergency mental health conditions. The receiving facility

renders psychiatric examinations and short-term treatment and stabilization.

Crisis Stabilization Unit: A CSU is a publicly-supported mental health facility that provides brief intensive services for individuals experiencing an acute crisis. The purpose of a CSU is to examine, stabilize, and redirect individuals to the most appropriate and least-restrictive treatment setting consistent with their needs.

Private Hospitals: Many private hospitals have psychiatric units and are designed as receiving facilities. Funding sources are different for public and private facilities. Some may take different forms of insurance, while others are able to serve individuals with no insurance.

Inpatient treatment is appropriate when someone is in a mental health crisis, specifically when that individual is dangerous to themselves or others. If the individual is in crisis and it is an emergency situation, the family member should seek help. The facilities will assist in making sure the individual receives appropriate treatment from the appropriate facility.

The family can be a vital part of the treatment team if the individual wishes for them to be involved. For families who are able to maintain contact with their relative, the following are questions to consider and discuss with staff both during and after hospitalization:

- What is the diagnosis, and what does it mean? Has this been discussed with the individual?
- What are the symptoms associated with the diagnosis?
- What specific symptoms could be the most problematic? What do they indicate?
- How can these symptoms be monitored?
- What medications have been prescribed?

- What side effect should be expected? Which of those are of concern?
- What is the treatment plan?
- Has the patient been educated individually or in class about his/her illness, management of symptoms and the medications prescribed? Do you think the patient understood the explanation?
- How often will the patient be able to interact with the treatment team?
- What steps can be taken to assist the individual with following the plan for services after being discharged?
- What appropriate housing and services are available after discharge?
- What should be done if an emergency occurs after discharge?

Ongoing Treatment

Serious mental illness is usually a long-term condition; families should plan ahead even if they are fortunate enough to have to deal with only a few episodes. Families who have lived with mental illness for a long time often describe how carried away they were at the time of the first episode and how they sometimes imprudently committed themselves to expensive treatments in expectation of cure that was never to be realized.

Most individuals need an early medical diagnosis and effective treatment, a safe stable place to live, and a chance to develop or relearn social and vocational skills. Some of the best places to look for support and services, over a long period of time, is through the local and state NAMI organizations, local community mental health centers and behavioral health clinics and centers. If services do not seem to be available, you may need to speak up, contact advocacy groups and state elected representatives, or even seek legal advice.

The ability of the person with the mental to learn about the illness is important in progressing toward a productive and meaningful life. It also is valuable for the person and his/her family to take responsibility for identifying and managing the symptoms of the illness. An understanding of the mental illness, symptoms and treatment, social skills training, and problem solving should be a part of both inpatient and outpatient care.

Programs like the NAMI education program Peer-to-Peer, NAMI Connection Recovery Support Group, ICCD clubhouses and drop-in centers also can play an important role through peer education, support and stabilization.

COPING WITH A RELATIVE WHO HAS A MENTAL ILLNESS

Reactions of Families and Friends

When mental illness strikes, family members are often overwhelmed by feelings of bewilderment, guilt, and denial. Exhaustion from being on call 24 hours a day may be coupled with frustration and anger. This

can be especially true when professionals are unable to accomplish what the family sees as basic assistance to help their relative regain a productive life.

It is not “unloving” to feel resentment in response to the behavior of the relative with a mental illness. Realizing the person is ill does not always overcome the hurt, dismay and anger felt by those trying to help. He/she may rebuff attempts to help, and may be fearful or accusatory toward those trying to help. Understandably, families, friends, and coworkers have problems with these symptoms, yet a hostile reaction will almost certainly intensify or lengthen an episode.

It is natural and necessary to grieve for the person your loved one used to be, but strength and determination are needed to meet the coming challenges. Caring, supportive family members can play a vital role in helping their relative to regain the confidence and skills needed for rehabilitation.

Please keep in mind the following:

- Avoid placing blame and guilt. The family did not cause the illness. Self-blame and blame leveled by others are destructive. Focus instead on the future and on what can be done to develop supportive living arrangements that will enhance the possibility of rehabilitation and recovery for your family member or friend.
- Remember other family members (siblings, grandparents) are affected too, and they probably are experiencing depression, denial, and guilt similar to your own feelings. Keep communication open by talking with them about their feelings and reactions.
- Both you and your relative/friend should learn all you can about the illness. Find out about benefits and support systems when things are going well; don't wait for a crisis.
- It also is important to address physical health problems as these exacerbate or become a considerable part of the mental health problem. The approach to care should be holistic.

Behavioral Issues

Some suggestions for coping with problem behavior:

- Plan ahead for situations when acute symptoms may recur. Discuss this with the primary therapist or treatment team.
- Learn to recognize signs of relapse, such as withdrawal or changes in sleeping and eating habits. The individual may be able to identify early signs of relapse (and should be encouraged to do so). He/she may also be able to tell you what method has worked in the past to relieve stress and gain control of symptoms. A visit to a psychiatrist or other therapist could help prevent a full-blown relapse, particularly when the person needs an adjustment of medications.
- Anticipate troublesome situations. If a certain family member is having trouble coping with a relationship, consider not inviting him/her if the ill family member will be present.
- Do not agree with stopping medications because the condition is “cured” or because the medication “makes me feel sick.” Refer these decisions to the doctor who prescribed the medication.
- Set reasonable rules and limits and stick to them. It can help to ask the doctor or a counselor to help you do this.
- Do not suggest that a person in crisis “pull themselves together.” If possible, he/she would. Not being able to do this is part of the illness. Remember, the suffering and distress of the person with mental illness is even greater than your own.
- Do not expect and insist that all disturbing habits be corrected at once. Focus on what is being accomplished, not what is going wrong.
- At times, people with mental illness suffer from memory loss or inability to concentrate; just repeat the information in a nonjudgmental way.

- Do not support or be critical of delusional thinking. The person with mental illness needs to be able to depend on a person who is objective, aware of what is really happening and able to kindly work with the truth.
- Your family member could hallucinate--seeing, feeling, hearing, or otherwise perceiving things not perceived by others. Be honest. Accept his/her perceptions as his/her own. If asked, point out that you are not experiencing the hallucinations. A discussion of how to respond to hallucinations and to other symptoms is an important part of the family support and education sessions that are offered by NAMI Pinellas and at some community mental health agencies and other health settings.

In support groups, information is shared about housing, sleeping, and eating problems, available social services, medications, missed expectations, the ill individual's lack of friends and loneliness, grief and loss, and fear of taking vacations.

Many people drop in at support group meetings for a few months, get answers and support for the hard times, and then move on. Other people may move from support groups into committee work. Often people make lifelong friends. Many people say, "I want to help. I don't want other people to go through what I went through." Some work at making real changes by becoming advocates for better services and care. Our NAMI affiliate assists in all these ways.

Support & Advocacy Groups

NAMI Pinellas provides support programs for families and friends as well as for individuals who are living with a mental illness. Providing this assistance is part of the primary mission of NAMI. It is important to share information about mental illness with others and to understand that serious long-term mental illness is not caused by something the individual has done. "We thought it was our fault," is said too many times. Family members and friends, because of their lack of information, may not be able to provide the support that is needed.

Unless they have lived with a family member or friend who is mentally ill, it is difficult for most people, sometimes even physicians, to understand the everyday trials and concerns of the rest of the family. It is comforting to know that other people deal with almost exactly the same issues and understand. Sometimes they have suggestions and answers; at other times they can only say "Yes, I know," and they do.

THE BAKER ACT: VOLUNTARY & INVOLUNTARY HOSPITALIZATIONS

Statutes governing the treatment of mental illness in Florida date back to 1874. In 1971, the Legislature enacted the Florida Mental Health Act, better known as the Baker Act, named for a state representative from Miami. The Act has been amended many times since it was implemented, with extensive revisions made in 1996.

Some key definitions used in Baker Act hospitalization include:

Voluntary Admission: An adult can apply for voluntary admission if he/she is found to show evidence of mental illness, is competent to provide express and informed consent, and is suitable for treatment. A child must not only be willing to be admitted, but also must have his/ her parent/guardian apply for the admission.

Mental Illness: Mental illness is defined as an impairment of the emotional processes that exercise conscious control of one's actions or of the ability to perceive or understand reality. This impairment must substantially interfere with a person's ability to meet the ordinary demands of living, regardless of etiology.

Express and Inform Consent: Consent that is voluntarily given in writing, by a competent person, after full disclosure to enable the person to make a knowing and willful decision without any element of force, fraud, deceit, duress, or other form of constraint or coercion.

Incompetent to Consent to Treatment: A person whose judgment is so affected by the illness that he/she lacks the capacity to make a well-reasoned, willful, and knowing decision concerning medical or mental health treatment. A physician must evaluate any person admitted voluntarily within 24 hours after arrival at a receiving facility to confirm the person's competence to provide express and informed consent for admission. If that individual is not competent, the person must either be discharged or involuntary placement must be initiated.

Persons on voluntary status who request discharge or who refuse or revoke consent to treatment must be discharged from the facility within 24 hours, unless the facility administrator files a petition with the circuit court for the patient's involuntary placement.

INVOLUNTARY EXAMINATION AND TREATMENT

A person may be taken to a receiving facility for involuntary examination if there is a reason to believe that he/she is mentally ill and because of his/her mental illness:

- The person has refused voluntary examination or is unable to determine whether examination is necessary;
- Without care or treatment, the person is likely to suffer from neglect resulting in real and present threat of substantial harm that can't be avoided through the help of others; and
- There is a substantial likelihood that without care or treatment the person will cause serious bodily harm to self or others in the near future, as evidenced by recent behavior.

An involuntary examination may be initiated by any one of the following means:

- A court may enter an order, based upon sworn testimony.
- A law enforcement officer, who has reason to believe the criteria is met.
- A physician, clinical psychologist, psychiatric nurse (ARNP), or clinical social worker, based on their examination of the person within the preceding 48 hours.

Regardless of the way the involuntary examination is initiated, law enforcement must take the person to the nearest receiving facility (or a centralized intake site), and the facility must accept (not necessarily admit) the person. If appropriate under state and federal law, the person may later be transferred to another facility.

Upon arrival at a receiving facility, a physician or clinical psychologist must examine a patient. The patient can't be released by the receiving facility without the documented approval of a psychiatrist or clinical psychologist.

A person can be held in a receiving facility for involuntary examination no longer than 72 hours. Within the 72 hour examination period, one of the following must take place:

- The individual must be released unless charged with a crime.
- The individual must be asked to give express and informed consent to voluntary placement.
- A petition for involuntary placement must be filed with the court by the facility administrator.

If a petition for involuntary placement is filed, a public defender will be appointed by the court to represent the person and a hearing will be scheduled within a few days. If the court finds that the person meets the criteria, he/she can be involuntarily hospitalized for a period of up to six months. However, facilities are required to discharge persons at any time they no longer meet the criteria for involuntary placement, unless the person has transferred to voluntary status.

INVOLUNTARY OUTPATIENT PLACEMENT

The 2004 Florida Legislature revised the Baker Act to add provisions for involuntary outpatient placement effective January 1, 2005. This allows court-ordered outpatient treatment for selected adults who have serious mental illness and meet the criteria established by the law.

A petition for involuntary outpatient placement can only be filed by administrators of community-based receiving facilities or state hospitals and only if the services proposed are currently available and funded for the person. The criteria that must be met by “clear and convincing evidence” include that the individual:

- Has a history of non-compliance with treatment and is unlikely to survive safely in the community without supervision, based on clinical determination;
- Has either at least twice within 36 months been involuntarily admitted to a receiving or treatment facility or received mental health services in a forensic or correctional facility; or engaged in one or more acts of serious violent

behavior toward self or others, or attempted serious bodily harm to self or others, within the preceding 36 months;

- Is unlikely to voluntarily participate in the recommended treatment plan and has either refused voluntary placement or is unable to determine whether placement is necessary;
- In view of the person’s treatment history and current behavior, the individual is in need of involuntary outpatient placement in order to prevent a relapse or deterioration that would be likely to result in serious harm to self or others;
- Is likely the individual will benefit from involuntary outpatient placement; and
- All available less-restrictive alternatives that would offer an opportunity for improvement of his or her condition have been judged to be inappropriate or unavailable.

The person must meet all criteria and a service provider must agree to provide the services before the court can order the treatment. Court-ordered treatment can be for a period of up to six months, but the court can consider periods of continued treatment if all the criteria listed above are still met.

MARCHMAN ACT: Substance Abuse

The Marchman Act provides individuals in need of substance abuse services with emergency services and temporary detention for substance abuse evaluation and treatment when required.

Marchman Act petitions that may be filed in Probate Court Records:

- An Ex Parte Petition for Involuntary Assessment and Stabilization
or

- An Ex Parte Petition for Involuntary Treatment

A Petition for Involuntary Assessment and Stabilization may be filed:

When there is reason to believe that a person is substance abuse impaired and:

1. Because of the impairment, he or she has lost the power of self-control with respect to substance use.
2. The person's judgment is impaired because of substance abuse and he/she is incapable of appreciating the need for, and is unable to make a rational decision in regards to, substance abuse services.
3. He/she has either inflicted, attempted or threatened to inflict, or unless admitted, is likely to inflict, physical harm on himself or herself or another.
4. The petition may only be filed by: The person's spouse or guardian, any relative of the person, a director of a licensed service provider, a private practitioner, or any three adults who have personal knowledge of the person's substance abuse impairment. In the case of a minor, only the parents, legal guardian/custodian or licensed service provider can file a petition.

Unlike the Baker Act, there is a filing fee required. Refer to the Schedule of Service Charges for current fees. The petitioner must also make arrangements for an available bed in a designated facility prior to submitting the petition for filing.

What happens after the petition is filed:

If the Court finds that the criteria have been met, an Order for Involuntary Assessment and Stabilization will be issued by the Court. The Court may set the case for a hearing, or the Sheriff may be ordered to transport the person to the designated facility. The facility then has 5 days to do an assessment. After the assessment has been completed at the facility, the petitioner may file a Petition for Involuntary Treatment of Substance Abuse for the patient.

A hearing date is set for the determination of the need for treatment. The assessment results are subpoenaed as evidence for the hearing, and a summons to appear at the hearing is issued and served on the patient. At the hearing the court will hear all the evidence and determine if the Order for Involuntary Treatment for Substance Abuse is warranted.

SEEKING TREATMENT FOR SUBSTANCE ABUSE DISORDERS

No single treatment is appropriate for all individuals. Types of treatment, as well as treatment goals, may vary from one person to another, and may even vary for the same person, depending on their stage of recovery. Substance abuse treatment programs generally incorporate the following goals (Schuckit, 1994; American Psychiatric Association, 1995):

- Reducing substance abuse and its effects or achieving a substance-free life
- Maximizing multiple aspects of life functioning
- Preventing or reducing the frequency and severity of relapse.

For many people, the primary goal of treatment is attainment and maintenance of abstinence, but this

People who have both substance abuse disorders and mental illness should receive treatment that addresses both issues. These individuals are said to have a co-occurring disorder, and treatment of their substance abuse disorder and mental illness should be carried out in an integrated way.

The initial stage of treatment is often detoxification. This process involves an evaluation, stabilization, and a fostering of readiness for the person to participate in a substance abuse treatment program. Detoxification in a medical setting with 24-hour supervision is recommended by the Substance Abuse and Mental Health Services Administration (SAMHSA) for people addicted to alcohol, sedatives, or hypnotics, and opiates. Withdrawal from these substances can often create medical complications for the individual that would require this type of monitoring.

could take numerous attempts and individuals often experience relapses before achieving a long-term substance-free life. Treatment programs usually try to minimize the effects of continuing use and abuse through education, counseling, and self-help groups.

These programs stress reducing risky behavior, building new relationships with drug-free friends, changing recreational activities and lifestyle patterns, and reducing the amount and frequency of consumption, often by encouraging individual responsibility for becoming abstinent. (American Psychiatric Association, 1995.)

Becoming alcohol or drug free, however, is only a beginning. Most people in substance abuse treatment have multiple, complex problems in many aspects of living. These may include medical and mental illnesses, disrupted relationships, underdeveloped or deteriorated social and vocational skills, impaired performance at work or in school, and legal or financial troubles. These conditions may have contributed to the initial development of a substance use problem or could have resulted from the disorder.

Efforts should be made by treatment programs to assist individuals in mending these problems so that they can achieve more responsibility in society and a greater satisfaction with life. This entails maximizing physical health, treating psychiatric disorders, improving psychological functioning, addressing marital or other family and relationship issues, resolving financial and legal problems, and improving or developing necessary educational and vocational

skills. Many programs also help participants explore spiritual issues and find appropriate recreational activities.

Increasingly, treatment programs also are preparing persons for the possibility of relapse and helping them

understand and avoid dangerous “triggers” of resumed drinking or drug use. Persons are taught how to recognize cues, how to handle cravings, how to develop contingency plans for handling stressful situations, and what to do if there is a “slip.”

FAMILY INTERACTION WITH LAW ENFORCEMENT

Calling 9-1-1

Having to call 9-1-1 is an extremely stressful decision. It is by definition **an emergency**. Not only do you have concern for the person about whom you are making the call, but you also want to make sure that law enforcement has enough information so that they will be able to respond effectively and safely.

Try to control the volume of your voice. When you shout over the phone, it is difficult for the 9-1-1 operator to understand what you are saying. Certainly this is a very emotionally charged time, but if the operator can only hear shouting, the information is not efficiently received. ***As calmly and clearly as possible, tell the operator the following if the information is available:***

- Your name
- Your address
- The name of the person in crisis
- Your relationship to the person
- That the person has a mental illness
- Name of the diagnosis (schizophrenia, depression, etc.)
- Any medication being used
- Has medication use stopped? If so, for how long?
- Describe what the person is doing now
- Do you feel threatened?

- Is there a history of violent acting out?
- Does the person hear voices?
- Does the person fear someone?
- Are there any weapons in the house? If so, try to safely remove them before calling 9-1-1
- Where the person is within the house
- Request a CIT Trained deputy / officer

WHEN LAW ENFORCEMENT ARRIVES

Have all the lights in the house turned on, so that all occupants can be clearly visible to the arriving officers. You can assist the officer who responds to the emergency call to establish his/her own ‘comfort zone’ by providing as much information as possible. This will allow the officer to know that you are not a threat, and also to know who the person in crisis is who might be agitated.

As calmly as possible, identify yourself and tell the officer as much information as you can, including:

- Who you are
- Who you have called about
- What your relationship is to the person
- That the person has a mental illness
- What kind of mental illness it is
- What medication is being taken
- Has medication use stopped? For how long?

- Whether or not the person is violent or delusional (paranoid)
- Any history of suicide attempt.
- An attending psychiatrist's and/or case manager's names and telephone numbers



Officers responding to a 9-1-1 emergency call are very focused when they arrive on the scene. First, they will make the scene safe for you, the person, and themselves. The more informed and at ease the officers are, the less likely someone will get injured or the situation will worsen.

Spend the time that is necessary answering all of the officer's questions. Answer directly and concisely. Do not ramble, but offer any advice you deem helpful. After this is done, they will usually be able to deal with the situation and to answer any questions. Although it is difficult in times of crisis, being patient is essential.

**CRISIS INTERVENTION TEAMS (CIT):
A PROGRAM FOR LAW ENFORCEMENT
OFFICERS**

If the individual with mental illness is in danger of physical injury, if his/her behavior is out of control, or if other persons are in danger, it is important to know what steps to take. Plan ahead by locating available sources for help, the number for the local police or sheriff's department, name and phone number of a mental health professional, community mental health center crisis emergency number, friends or neighbors who may be of help, and the NAMI Sarasota County Helpline telephone number. Keep these numbers posted by the telephone along with 2-1-1 services.

Talk with the person's social worker or psychiatrist and with the community mental health center so you will know how to obtain services when needed for your loved one.

If you sense deterioration in your relative or friend's mental condition, try to find out what is going on. Everyone occasionally has a bad day. However, there are usually early warning signs that signal problems, such as changes in sleep or social activities or increased hostility or suspiciousness. Encourage the individual to see a psychiatrist or social worker. ***The object is to avert a crisis!***

If you should have to call for help in a crisis, have information available about the family member or friend's diagnosis, medications, previous hospitalization (s), and a description of the specific behavior that precipitated the crisis. It may be useful to have several copies of such information to give to the police and to mental health professionals.

However, if the individual needs crisis intervention, you might need to contact a CIT officer. The ***Crisis Intervention Team (CIT) Program*** is composed of specially trained uniform patrol officers who respond to calls related to a person having a mental illness crisis. Officers can face challenges from or about persons attempting suicide, threatening harm to others or displaying other dangerous symptoms or

behavior. This requires new and special talents and knowledge.

Throughout the state, more than 20,000 law enforcement officers have been trained in the nationally acclaimed 40-hour CIT course. The faculty, who are all professionals, family members or consumers from the local mental health community, volunteer their time and talents to provide the most up-to-date information to law enforcement officers, regarding mental illnesses, medications, de-escalation techniques, Baker Act authority, and unusual behaviors such as suicide, homicide, and aggressiveness. The course includes several hours spent in discussion with persons with mental illness who share their past interactions with the law.

CIT was originated by the Memphis, Tennessee, Police Department. CIT trained officers are capable and willing to routinely and repetitively handle this type of non-criminal call for service in addition to their normal patrol duties. Repeated opportunities to develop techniques and gain knowledge of the mental health system are of paramount importance for successful and safe interventions.

Dispatching CIT trained officers on calls involving persons having a crisis due to a mental disorder demonstrates CIT's value to the community through the saving of lives, time and money.



The Memphis model CIT programs now are in place in cities across America, as well as in other countries. To continue program development, an International

CIT organization was created whose primary purpose is to facilitate understanding, development and implementation of Crisis Intervention Team (CIT) programs throughout the United States and in other nations worldwide. CITI promotes and supports collaborative efforts to create and sustain more effective interactions among law enforcement, mental health care providers, individuals with mental illness, their families and communities, and also to reduce the stigma of mental illness.

CIT International works to accomplish this purpose by raising public and stakeholder awareness through education and outreach, establishing and disseminating recommended standards for developing, implementing and sustaining crisis intervention programs, providing assistance to communities interested in developing CIT programs, supporting research, improving public health and safety, evaluation of CIT programs and partnering with CIT programs in various localities to hold annual International CIT Conferences.

Jail and Jail Diversion

According to the Surgeon General, the criminalization of mental illness is the silent epidemic of our times. One attorney stated our jail and prison system is perhaps the greatest danger facing persons with mental illness today.

The number of inmates with a mental illness in Florida prisons and the number of individuals with a mental illness incarcerated in county jails have grown at an alarming rate since the mid 1980's. Placing individuals who have had a public crisis with a mental illness in jail, or sending them to a prison, creates a vicious cycle as they are generally not able to receive all of the care and support they need to manage their

mental illnesses. When released, they tend to recycle back to jail and/or prison.

Early treatment, early diagnosis and early intervention when symptoms escalate, may well succeed in avoiding incarceration. When this is not possible, NAMI members have worked with state and local law enforcement agencies and community health centers to make it possible to treat rather than punish persons who are mentally ill, by diverting them from jails and courts into residential treatment programs. This is true for both adults and children who find themselves in the juvenile justice system.

Individuals living with a mental illness who are facing legal problems should seek legal assistance. If they cannot afford a private attorney, Florida Legal Aid Service or the local State of Florida Public Defenders Office, mental health advocates, and others should be able to help.

The attorney representing the individual should look into release of the person on bond as quickly as possible to allow him/her to get into treatment before the situation worsens. In cases where this may not be possible, the attorney should make an appropriate motion to ensure that proper psychiatric treatment and support are available while either release or trial is pending.

It also is helpful to find an attorney who has some understanding of brain disorders, the legal defenses available, and their impact of on the individual who is

charged. If the offense is of a minor nature, a skilled attorney may be able to arrange for a transfer to a psychiatric facility for treatment in exchange for delaying the criminal case with ultimate dismissal of the charges. Compliance with the recommended treatment may be ordered by the court as a condition of probation or even an alternative to trial or a substitute for serving time in jail.

It is not unusual that contact with the criminal justice system may provide the first opportunity to identify mental illness and connect the individual with community mental health centers. While it may not always be possible to avoid the original incident and incarceration, it should be the goal of the family, the person with mental illness, and the mental health system to eliminate future incidents.

FLORIDA ASSERTIVE COMMUNITY TREATMENT (FACT)

FACT is a program supported by public funding that reduces hospitalization, homelessness, and criminal incarceration. Services are delivered to help those with the most chronic and persistent mental illnesses (schizophrenia, bipolar disorder, and other illnesses that cause pronounced disability) to live in the community. The program is an official, funded program in Florida and was approved by the 1999 Florida Legislature.

FACT is an effective, evidence-based, outreach oriented, service-delivery model for people with severe and persistent mental illnesses. Using a 24-hour-a-day, seven-day-a-week, team approach, FACT delivers comprehensive community treatment, rehabilitation and support services to its clients in their homes, at work or in the community. FACT teams are coordinated combinations of psychiatrists, nurses, social workers, substance abuse treatment specialists, vocational rehabilitation counselors, and peer counselors. The majority of FACT services are delivered where clients live, work, and spend their leisure time--not in the program office.

The team uses a positive, persistent, practical approach offering: (1) direct provision of psychiatric care and assistance with general health care; (2) help on managing symptoms of the illness; (3) immediate crisis response; (4) the most effective and appropriate anti-psychotic and anti-depressant medications; and (5) supportive therapy. FACT team members provide practical on-site support in coping with life's day-to-day demands including: help obtaining **financial supports** and **housing**, assistance with **housing tasks** so a person can live in regular housing alone or with a roommate, help with **socializing**, **treatment** for clients with **co-existing substance abuse**,

supportive employment services and **job placement**, assistance with **legal issues**, and support, education, and skill-teaching for **families**.

FACT – Comprehensive Care

Unlike traditional community services, FACT teams: (1) have one staff member for every ten clients (a team consisting of 10 can serve up to 100 clients) plus at least 16 hour a week of a psychiatrist's time for every 50 clients; (2) treat both psychiatric and substance abuse disorders at the same time; (3) take services to the client rather than requiring clients to come to the office; (4) provide team case management and include the individual as a member of the team, which aids in continuity of care in case a staff member leaves; (5) help clients who have children to strengthen their parenting skills; (6) coordinate provisions of psychiatric care with general medical care and dental care; (7) continue to see a client who is in a hospital or jail, which often facilitates an earlier return to the community; (8) employ a psychiatrist who is a full team member, who is not a consultant to the team, who is able to participate and teach staff how to carry out treatment; and (9) lessen the family's burden of providing and coordinating care so a FACT client and his/her family can relate more easily as family members.

Fact is Rehabilitation & Recovery Oriented

FACT helps clients regain control of their lives and move ahead with their plans. The FACT approach helps people live in regular housing, socialize in their community, and return to school or work. FACT's attention to basic needs (housing, medical care,

income) enables persons with mental illness -- even those with severe disabilities -- to regain stability; assess their goals, and take steps toward recovery. The relatively low cost of FACT care is an added benefit of the program. In many communities, the cost is less than the cost for inappropriately placing a person with mental illness in jail or for confinement in a state hospital.

Fact Clients

The FACT program successfully treats and rehabilitates people who don't keep office

appointments, people who have co-occurring psychiatric and substance abuse disorder, people with severe and persistent mental illness, people with socially disruptive behavior who are at high risk for arrest and incarceration, people who are high users of emergency and inpatient hospital services, people who cannot meet their own basic needs and are living in substandard housing situations or who are homeless, and people who are at risk of placement in state hospitals.

HOUSING

Obtaining independent housing with access to services within the community is the primary goal and a fundamental value shared by people with mental illnesses. Having one's own home -- whether it is an apartment, a furnished room or a house -- is the cornerstone of independence for people. With stable, permanent housing, people with mental illnesses are able to achieve other important life goals including improved health, education, job training and employment. However, access to affordable housing that also is convenient to services for people with mental illness is becoming increasingly difficult.

Public mental health agencies and the mental health community in general may be able to assist in gaining access to housing that may include the following:

Residential Treatment Facilities: These homes are generally associated with the Community Health Centers in some way and offer group activities as well as rehabilitative services. They are generally considered transitional and are often reserved for individuals being discharged from state hospitals or community hospitals that are under contract with the Florida Department of Children and Families.

Assisted Living Facility (ALF): These homes are licensed by the Agency for Health Care Administration (AHCA) to provide 24-hour care and supervision of residents. Activities and rehabilitation services are limited in these housing settings.

Supported Housing/Supported Living: These services assist persons with substance abuse and psychiatric disabilities in the selection of the housing of their choice. These services also provide the necessary services and supports to assure their continued successful living in the community and transitioning to further independence.

Independent Living Alone / With Family: This arrangement works for persons who are fairly self-sufficient. Local agencies can be helpful with housing arrangements or in securing the assistance needed for independent living.

Nursing Homes: These facilities are designed for people who need continuous care 24 hours a day. Generally there are other medical problems in

addition to the mental illness in order to qualify, or the diagnosis is a form of dementia.

Adult Foster Care Homes and Caregivers:

Caregivers in the foster care homes are responsible for the care, support and well-being of the clients who live in the home. Adults placed in these homes are encouraged to feel like a member of the family, participating in family activities and responsibilities.

The Alternative Family Program: The Alternative Family Program is a residential program that provides care within licensed and certified homes for adults and seniors with severe and persistent mental illness. AFP Homes are licensed as Adult Foster Care Homes.

Other transitional, temporary and permanent housing options could become available, when funding is identified to support additional options.

CLUBHOUSE INTERNATIONAL

Based on the Fountain House Model of New York City, clubhouse programs are restorative communities for persons recovering from mental illnesses. Not a residential facility, clubhouse programs operate during normal business hours and offer social and vocational training in a stigma-free environment. Participants are correctly referred to as “members” rather than clients or patients. Based on a wellness approach, members develop social and vocational skills, pursue education goals, and obtain employment. Clubhouse programs use work as the means to help members rebuild their lives.

Vocational Training

- Members participate in hands-on vocational training in a wide range of skill areas.
- Members work side by side with staff.
- All training activities are offered in a normalized work environment.
- Member skills and talents are utilized.
- Self-confidence is restored, stamina is developed and concentration increased.

Technology: Use of Microsoft Office suite, Adobe InDesign suite, electronic membership card system, data entry, and training on both PCs and iMacs.

Banking: Money management and use of QuickBooks.

Communications: Use of social media, graphics and design, videography, telephone reception, and newsletter publication.

Training Areas

Culinary Arts: Menu planning, budgeting and shopping, food preparation, service and cleaning, maintenance, and money management.

Retail Sales: Pricing, sorting, sales, Point of Sale cashier work, money management, and customer service.

Outreach: Reach out to members who are hospitalized or who experience difficulty with community reintegration.

Benefits and Support Assistance: Assistance with acquisition or management of governmental benefits, including SSI / SSDI.

Transitional Employment Program

In partnership with area businesses, clubhouse programs help members reenter the world of paid employment through a unique approach called Transitional Employment (TE). The average TE placement lasts 6-9 months and is a stepping stone to subsequent career-based employment.

Highlights of Transitional Employment (TE)

- All job placements are entry-level positions.
- TE positions are designed to facilitate work adjustment.
- Prevailing wages are paid.
- Members develop confidence and job references.
- Placements are temporary and part-time.
- Consecutive TE placements help develop basic work skills and an employment history.
- TE removes the barriers to the workplace.
- Hospitalization or lack of work history do not pose barriers to employment.
- Interview skills are not required to secure employment.

Evening & Weekend Program

The evening and weekend program is designed to meet social and recreational needs. Social events occur only during the evenings, weekends and holidays--not during normal business hours.

Activities include educational or cultural events, as well as recreational outings such as bowling, movies, or sports. The evening and weekend program allows members who are employed to have continued support when daily participation diminishes because of their work schedule.

Community Support

Members receive assistance with entitlements and services including housing, quality medical care, psychological, pharmacological and substance abuse services. Staff also assist with member needs by providing clinical, legal and financial referrals.

Supported Education

Members receive assistance and encouragement in the pursuit of educational goals: identification of a particular field of interest, selection of academic institutions, and completion of the application process.



A Recovery through Work Partnership

In Sarasota Co., services will be offered at **Vincent Academy, 1910 Glengary St., Sarasota.**

Vincent Academy is a membership community promoting vocational and social well-being. Members and their families pay tuition to ensure the financial sustainability of Vincent Academy. Financial aid is available for eligible applicants. Biweekly Discovery Tours offer the chance to visit the Recovery through Work program, meet the members and a representative of the Board of Directors. For more information, call **941-374-9652** or visit them on-line at **www.vincenthouse.org**.

NAMI strongly supports Clubhouse International as a necessary step in recovery for those living with a mental illness. Ideally, clubhouse programs should be available in every major community.

REHABILITATION SERVICES

Psychological rehabilitation progress should include the following: recreational activities, social skills training, employment related training and assistance, and assistance toward independent living. Limited rehabilitation services are available through some community mental health centers as well as private facilities. Assistance with education, training, and employment also is available through State of Florida Department of Labor & Employment Security, Vocational Rehabilitation Division.

The Americans with Disabilities Act (ADA) passed by Congress in 1990, is an important federal law which prohibits discrimination against any person with a disability. It also covers individuals who have a history of disability or who are regarded by others as impaired, even if they are not. This would include, for example, people who have had psychiatric treatment in the past but who are now fully recovered.

The ADA covers employment, public (government) services, and public accommodations. Employers cannot discriminate against an individual with a disability, including mental illness, if the person is otherwise qualified, by skills and background for the job. The employer also must provide “reasonable accommodations” that will allow an otherwise qualified person to perform the essential duties of the job.

For more information on the ADA, contact:
US Department of Justice
950 Pennsylvania Avenue, NW
Civil Rights Division
Disability Rights Section - NYA
Washington, D.C. 20530
Phone: 800-514-0301
Website: www.ada.gov

NAMI’S MULTICULTURAL ACTION CENTER

As part of its mission NAMI is pledged to improving access to treatment and the quality of care for all Americans with mental illness and their families. Thus, NAMI has created a Multicultural Action Project at its national headquarters in Arlington, Virginia. The Center’s strategies include the following:

- More centrally involved members of disadvantaged communities in these efforts.
- Develop and disseminate culturally competent direct service support models in the field.
- Decrease stigma through public education models that address specific racial and cultural barriers.
- Improve mental health policy development at the local, state, and national levels by increasing grassroots participation.

Increasing Involvement of Racial & Ethnic Minorities

By forming coalitions with grassroots groups that serve diverse communities, and developing cross-cultural alliances that address mental illness, the Project is building a multicultural grassroots network that improves understanding of mental illness among members of diverse communities and increasingly represents all people affected by mental illness.

Cultural Competency

NAMI's Multicultural Action Center is equipped to provide the latest research and thinking on such issues as:

- over-diagnosis of disorders based on race
- the overlay of poverty on different racial and ethnic communities

- history of state repression and its impact on accessing care
- cultural prohibitions against seeking help

Public Education

Misinformation and overwhelming stigma continue to surround mental illness. To address this, public education messages are often developed to reach a broad audience, bypassing specific cultural and material realities that racial and ethnic minorities face. Through partnerships with organizations that directly serve racial and ethnic minorities, NAMI's Multicultural Action Center is drawing on community-based expertise to create public education messages that address complex barriers to treatment and care.

CULTURAL DIVERSITY

(From the Surgeon General's Report for Mental Health)

Overview Of Cultural Diversity & Mental Health Services

Racial and ethnic minority groups are generally considered to be under-served by the mental health service system. A constellation of barriers deters ethnic and racial minority group members from seeking treatment, and if individual members of groups succeed in accessing services, their treatment could be inappropriate to meet their needs.

Research documents that many members of minority groups fear, or feel ill at ease with, the mental health system. Research and clinical practices have propelled advocates and mental health professionals to press for "linguistically and culturally competent

services" to improve utilization and effectiveness of treatment for different cultures.

Introduction To Cultural Diversity and Demographics

Racial and ethnic populations differ from one another and from the larger society with respect to culture. The term "culture" is used loosely to denote a common heritage and set of beliefs, norms, and values.

The historical experiences of ethnic and minority groups in the United States are reflected in differences in economic, social, and political status. The most measurable difference relates to income.

Many racial and ethnic minority groups have limited financial resources. In 1994, families from these groups were at least three times as likely as white families to have incomes placing them below the federally established poverty line.

Cultural identity imparts distinct patterns of belief and practices that have implications for the willingness to seek, and the ability to respond to mental health services. These include coping styles and ties to family and community.

Coping Styles

Cultural differences can be reflected in differences in preferred styles of coping with day-to-day problems. Consistent with a cultural emphasis on restraint. Asian American groups encourage a tendency not to dwell on morbid or upsetting thought. They have little willingness to behave in a fashion that might disrupt social harmony. Their emphasis on willpower is similar to the tendency documented among African Americans to minimize the significance of stress, and, relatedly, to try to prevail in the face of adversity through increased striving.

Culturally rooted traditions of religious beliefs and practices carry important consequences for willingness to seek mental health services. African Americans and a number of ethnic groups, when faced with personal difficulties, have been shown to seek guidance from religious figures.

Many people of all racial and ethnic backgrounds believe that religion and spirituality favorably impact upon their lives and that well-being, good health, and religious commitment or faith are integrally intertwined.

Cultural also imprints mental health by influencing whether and how individuals experience discomfort

associated with mental illness. When conveyed by tradition and sanctioned by cultural norms, characteristic modes of expressing suffering are sometimes called “idioms of distress”. Idioms of distress often reflect values and themes found in the societies in which they originate.

One of the most common idioms of distress is somatization, the expression of mental distress in terms of physical suffering. Somatization is prevalent among person from a number of ethnic minority backgrounds. Epidemiological studies have confirmed that there are relatively high rates of somatization among African Americans.

Among culture-bound syndromes found among some Latino psychiatric patients is ‘ataque de nevios’, a syndrome of “uncontrollable shouting, crying, trembling, and aggressions” typically triggered by a stressful event involving family. A Japanese culture-bound syndrome, ‘Taijin kyofusho’, is an intense fear that one’s body or bodily functions give offense to others. Culture-bound syndromes sometimes reflect comprehensive systems of belief, typically emphasizing a need for balance between opposing forces or the power of supernatural forces. Belief in indigenous disorders and adherence to culturally rooted coping practices are more common among older adults and among persons who are less acculturated.

Family & Community As Resources

Ties to family and community, especially strong in African, Latino, Asian and Native American communities, are forged by cultural tradition and by the current and historical need to assist arriving immigrants, to provide a sanctuary against discrimination practiced by the larger society, and to provide a sense of belonging and affirming a central help-culture or ethnic identity. Family solidarity has

been invoked to explain relatively low rates among minority groups of placing older people in nursing homes. Families play an important role in providing support to individuals with mental health problems. A strong sense of family loyalty means that, despite feelings of stigma and shame, families are an early and important source of assistance in efforts to cope, and that minority families may expect to continue to be involved in the treatment of a mentally ill member. Investigators have demonstrated an association between family warmth and a reduced likelihood of relapse.

BARRIERS TO THE RECEIPT OF TREATMENT

The under-representation in outpatient treatment of racial and ethnic minority groups appears to be the result of cultural differences as well as financial

organizational and diagnostic factors. The service system has not been designed to respond to the cultural and linguistic needs presented by many racial and ethnic minorities.

Among adults, the evidence is considerable that persons from minority backgrounds are less likely than whites to seek outpatient treatment in the specialty mental health sector. This is not the case for emergency department care, from which African Americans are more likely than whites to seek care for mental health problems. Language, like economic and accessibility differences, can play an important role in why people from other cultures do not seek treatment.

LEGAL CONSIDERATIONS

Advance Directives

All individuals, those with or without any type of mental or physical illness, are advised to prepare Advance Directives for care and decision making should they become unable to make those decisions themselves. There are many components to Advanced Directives, one of which is the appointment of a *healthcare surrogate*, which is a person who can make healthcare decisions, if an individual is unconscious or otherwise deemed incapable of making those decisions.

Once a physician or the courts decide that a person cannot make well-reasoned and knowledgeable decisions the healthcare surrogate named in the Advance Directive is immediately notified to make treatment decisions the person would make if competent. The surrogate can access the person's clinical record, release information, and apply for public benefits.

There are other legal and personal ramifications to the development of effective Advance Directives, and families and individuals are advised to contact their legal resource or Legal Aid Services for more information. It also is important to know that Advance Directives and the designation of a healthcare surrogate can be rescinded at any time. They are not permanent decisions.

GUARDIANSHIP

If there is a concern that an individual with mental illness may become too incapacitated to make reasonable decisions concerning medical treatment,

finances, and their care in general, the individual's support person should consider requesting that the individual sign a health care surrogate form.

Guardianship also could be appropriate in some cases. This is a court-appointed responsibility that is awarded to an individual after the person with a mental illness becomes incompetent. The court would then assign responsibility to a family member or a professional guardian.

The courts have significant powers in the case of a person with mental illness becoming incapacitated which includes the authority to withdraw the rights to

vote, marry, travel, contract, determine residence, have a driver's license, sue and defend lawsuits, seek or retain employment, consent to medical treatment, personally apply for government benefits, make decisions about social environment or social aspects of life, and/or manage property and income or make any gift or disposition of property. The Guardian must file an annual accounting of finances.

Durable Power Of Attorney

An attorney can draw up a *Durable Power of Attorney*, which may include the right of the designated agent to handle financial matters, give medical consent, or provide other assistance in the event of incapacity. It is important to recognize that while the agent is legally responsible for judiciously handling matters, there is no required accounting of funds or manner of care.

FINANCIAL CONSIDERATIONS

FEDERAL AND STATE PROGRAMS SSI, SSDI, MEDICAID, MEDICARE

Often a family will support an adult child who is mentally ill for a long period of time. Sometimes this requires the use of precious savings, which may not be necessary. Many do not realize that mental illness qualifies as a disability and that the disabled individual may be eligible for income and healthcare assistance.

There are two federal disability programs: SSI (Supplemental Security Income) and SSDI (Social Security Disability Income). The SSDI program is designated for people living with a disability. Application can be made at any local Social Security office. For information or appointment at the local Social Security office, call 1-800-772-1213 weekdays. Information you may need in contacting the Social Security office might be the individual's birth certificate or other proof of age and citizenship, information about the home where he or she lives, work history, any sources of financial support, dates of any military service and names, addresses, phone numbers of doctors, hospitals, clinics and institutions where treatment has been received, with dates of treatment. Requirements of the department change and some information may no longer be needed.

ELIGIBILITY

The amount paid under SSI and SSDI varies, and some individuals are eligible for both sources of funding. Those who live independently may receive a larger amount than those who are supported at a relative's home. To be eligible for SSI based on disability, a person must have a physical or mental

impairment. In the case of a child, the impairment should prevent the child from performing normal activities of daily living. In the case of an adult, the disability would prevent the adult from doing any substantial gainful work. The disability of either a child or adult is expected to last at least a year or to result in death. In both the cases of the adult or child, the individual or family has little or no income or resources. To be eligible for SSDI the person must: have worked and paid Social Security, or be an unmarried son or daughter (with rare exception) who became disabled before age 22, who has a parent eligible for retirement / disability/ death benefits. The disabled child does not have to be dependent or financially supported by the parent. The recipient also must have a physical or mental impairment that prevents the person from doing any substantial gainful work that has lasted or is expected to last for at least one year.

APPLICATION FOR SSI AND SSDI FUNDING

Benefits are retroactive only to the date of application, so it is important to apply as early as possible and plan a persistent follow up. The application process can be expedited if medical records are obtained in advance. This includes records from hospitalizations, physicians, case managers, and other providers. An individual can be assisted in this process if he/she signs a release to allow a family member or authorized representative to assist. Applications should include a listing of all physical and mental conditions that may be considered as disabilities. The Social Security Administration has to consider multiple disabilities when assessing eligibility for benefits.

If benefits are denied, the ruling may be appealed by requesting: (1) reconsideration, (2) a hearing before an administrative law judge, (3) a review of the decision by the appeals councils, or (4) civil action in a federal district court. There is a 60-day appeal time period between each of these steps. There is a National Organization of Social Security Claimants who helps individuals find representatives to handle SSA Appeals at 1-800-431-2804. The Departments of Legal Aid around the state handle SSA appeals and waiver requests usually without cost, when the case is ready to go for the third appeal in front of an administrative law judge.

Many consumers and their families find it a difficult task to obtain the required papers and information and to work their way through the application and review process. There are attorneys who specifically handle these types of cases. While waiting on a decision on eligibility for SSI or SSDI, a disabled person may qualify for State Disability Assistance (SDA), food stamps, or assistance with emergency food and shelter through the Department of Social Services (DSS).

Importantly, when an individual applies for SSI or SSDI, he/she can request that SSA assess them for presumptive disability (PD). This will give an individual the opportunity to receive SSI and Medicaid for three months while Social Security is processing their claim for benefits. PD should be requested in writing and usually can be considered if it is obvious that an individual is too disabled to work for longer than a year. If an individual is not found eligible, repayment is not required. The Disability Determinations staff is required to make an eligibility decision usually within 90-days.

It may be desirable to have a representative designated to receive payments if the individual with the mental illness is unable to manage his or her funds. This representative may be a relative or an agency or some other designated individual. Family should consider designating someone outside of the family to handle funds so that they can concentrate on support and care.

There is provision for SSI and SSDI payments to continue for a limited time while the individual is in a hospital or other institution. This is designated to assist the person to maintain existing housing arrangements during a short period of hospitalization. Applications for this benefit must be made to the Social Security office.

Under many circumstances, Medicaid is available for those who qualify for SSI. In Florida, Medicaid application can be made at any district office of the Department of Children and Families.

CONSERVATORSHIP

Conservatorship is the designation by the Probate Court of a person to manage substantial income or property for another person. However, if the only income is from SSI or SSDI, conservatorship is not necessary. In this case, a parent or other person can be appointed representative payee by the Social Security office to handle financial matters.

WILLS, TRUSTS AND ESTATE PLANNING

If an individual with mental illness qualifies for SSI benefits, it is very important for the family to plan ahead so that SSI payment and Medicaid will not be lost through inadequate estate planning. By inheriting property or money, the individual may be disqualified for these entitlements, which cover the cost of residential services and medical care. Some families have drawn up a will, which disqualifies the relative

who is mentally ill. Others have set up a Special Needs Trust with another relative as trustee, or with a financial institution and another relative as co-trustee. The Special Needs Trust must be restricted so that it cannot be used for basic living costs; a lawyer who specializes in this work should be consulted.

Supplemental Needs Trust – Many parents are not aware that special planning tools are available to protect assets for disabled family members. A Supplemental Needs Trust is a special trust designed to provide funds for a disabled individual's needs without putting public benefits at risk. Parents or other family members can establish these trusts during life or through various estate plans.

Supplemental Needs Trusts are used to shelter funds for the benefit of the disabled person. These funds are typically the result of an inheritance or personal injury award. Funds are available for anything not provided by public benefits. Within a properly drafted trust, the funds are not considered in determining eligibility for public benefits.

Proper estate planning includes not only planning for others after a caregiver's death, but also planning for the caregiver during his or her lifetime. The family must plan for the possibility that the caregivers themselves could become disabled as they age. There are many ways to make certain that the estate is preserved for the disabled child while still meeting the needs of the caregiver during their lifetime.

Consult an attorney who specializes in these issues, as laws can change.

MEDICARE

Medicare is a health insurance program for people age 65 or older, certain people with disabilities who are under age 65 and people who have permanent kidney failure. Medicare provides basic protection

against the cost of health care, but it does not cover all medical expenses or the cost of long-term care.

Medicare and Medicaid are not the same program.

Medicare is operated as a joint venture between federal and state governments. Medicare has three parts: Part A – Hospital Insurance, which helps pay for inpatient care in a hospital and skilled nursing facilities, home health care and hospice care; Part B – Medical Insurance, which helps pay for doctor's services, out-patient hospital care and many other medical services and supplies; Part D, which pays for drugs. Medicare covers a number of health care needs, some of which require co-pays. For a detailed explanation of Medicare services available and on how to apply, go to Medicare's website at www.medicare.gov or The Centers for Medicare and Medicaid Services (CMS) at www.cms.hhs.gov. You may also call 1-800-Medicare (800-633-4237).

Medicare Costs

There is a monthly premium for Medicare services and other out-of-pocket costs. When services are delivered, a deductible or co-pay may apply. If someone cannot afford to pay the Medicare premiums and other costs, he or she may also get help from the state through an assistance program. Assistance programs are for people who are entitled to Medicare and who have very low income.

MEDICAID

Medicaid, a program funded with federal and state dollars, helps people who cannot afford medical care, such as people who have a low income and have limited savings accounts and other assets. It is for people of any age. It usually covers the full cost of health care in some cases; however, some patients may have to share a part of the cost. If someone qualifies for Medicare, he or she also could be qualified for Medicaid, depending upon income and

other related factors. The federal government sets general guidelines for Medicaid, but each state legislature decides the following:

- Who qualifies for Medicaid
- What services will be covered
- How much to pay for the services
- How to run the Medicaid program

In Florida, eligibility is determined by the Florida Department of Children and Families and the Medicaid program is run by the Agency for Healthcare Administration (AHCA).

The Future of Florida's Medicaid program is unclear. For up-to-date information, contact The Centers For Medicare and Medicaid Services at www.cms.gov. The following is a short list of services that may be covered differently in different parts of Florida depending on the Medicaid program operating in the area.

- Community mental health services
- Prescription drugs
- Vision exams and glasses
- Hearing exams and hearing aids
- Dental service
- Home and community based services including AIDS services and assisted living for the aged and disabled
- Adult health screenings for adults 21 and older
- Hospice services
- Care in intermediate care facilities for people with developmental disabilities
- Durable medical equipment and supplies including ambulatory equipment (canes, crutches, walkers, etc.)
- Physical, occupational, respiratory and speech therapy
- Ambulance and other transportation services

- Special child health services
- Under Medicaid Reform, the state has also authorized other services at the Managed Care Organization's discretion

WORK ACTIVITY

There are several options available to individuals who are living with a disability and are able to and desire to work. Assistance with education, training and employment may be found by contacting Florida's Division of Vocational Rehabilitation at 866-515-3692. Other programs available include the following:

Tickets to Work – Persons who are current beneficiaries of Social Security could be eligible to participate in the Social Security Administration's Ticket to Work program. The "Ticket" is a voucher that can be used to obtain employment-related supports and services from approved service providers known as *Employment Networks*. Tickets also can be placed with the Division of Vocational Rehabilitation. Participation in the Ticket program is voluntary for both the Social Security beneficiary and the Employment Network.

PASS Program – The Plan to Achieve Self Support (PASS) is an SSI program to help individuals with disabilities return to work. PASS lets disabled individuals set aside money and/or assets he/she owns to pay for item or services needed to achieve a specific work goal.

This could be a number of things and can include items such as supplies to start a business, school expenses, transportation, uniform requests and training among others. In order to participate in the PASS program, an individual needs to contact the local SSA office and obtain a PASS form (SSA-545-BK). Additional information can be obtained by

contacting the Social Security office--800-772-1213 or visiting their website at www.socialsecurity.gov.

Other Employment Assistance – As time goes on, there could be other resources available to assist individuals with mental illness in obtaining

employment. Organizations such as Clubhouses, Abilities, Inc., and college/university placement offices, as well as many employers at local companies, now offer to assist persons with disabilities in finding meaningful work.

WORKING WITHIN THE SYSTEM

TIPS ON GETTING THE HELP YOU NEED

Individuals living with a mental illness, their family members and friends need to know how to be effective in getting help when someone is seriously mentally ill. The following suggestions will help:

- Keep your records updated and current. List names, addresses, phone numbers, dates of crisis events, admissions and discharge dates of hospitalization. Make notes of conversations and conferences. Make copies of everything that is mailed. Keep all notices and letters and keep all of these items in an easily accessible file folder.
- If acting on behalf of an individual with a mental illness, keep that person informed about everything you plan to do and obtain approval when appropriate.
- Be patient, polite, and keep conversations to the point.
- Do not accept any attempts to be intimidated and do not intimidate the professionals and caregivers.
- Do not accept vague answers or statements that seem confusing. For example, if a clinician says, "We are observing your daughter carefully," realize that this statement provides no information of substance.
- Write letters of appreciation when warranted. Write letters of constructive criticism only when

necessary. Address communications to the decision maker in an organization and consider sending copies to your legislators or other State officials.

- Learn communication techniques in getting information. For example, instead of saying "Who should I call now?" say "If this was your son, what would you do next?" General questions can always be asked, such as "What is the average length of stay for this type of condition?" or "How have you helped others in this type of situation?" The vast majority of professionals want to help, but are limited on being able to specifically give detailed advice.
- Do not be afraid or ashamed to acknowledge that you are the relative of a person who has a mental illness.
- Finally, be assertive! You are paying, either directly or with your taxes, for mental health services. You are entitled to information, respect and courtesy and are not asking for favors. You are simply helping to get the job done.

SERVICES FOR VETERANS

Since 2001, the United States has deployed more than 1.5 million soldiers to fight the war. Upon returning home, 25% of these combat veterans have sought help for mental illness and have been diagnosed with Post-traumatic Stress Disorder (PTSD). Half of these men and women had two or more distinct mental health diagnoses. The youngest group of these veterans (aged 18-24 years) were at greatest risk for receiving mental health or PTSD diagnoses compared with veterans 40 years or older.

Traumatic brain injury (TBI) and depression, as well as other mental illnesses, are major concerns in the veteran population. When husbands, wives, mothers and fathers now living with mental disorders come home, many families are left wondering what to do. NAMI believes it is our duty to honor and help these service men and women and their families.

An initiative between NAMI and the Veterans Health Program and the Veterans Health Administration (VHA) to include NAMI's Family-to-Family program at VHA facilities has already yielded impressive results. After taking the course, family members have reported they had an improved understanding of mental health issues, and realized they were not alone! One mother said she has become less judgmental toward herself and is more confident that she can explain what goes on in her son's mind.

NAMI is a pioneer in peer education, giving families of individuals living with mental illness a place to turn to find a strong network of support and tools derived from the lived experience of other family members. The VA has realized that if you want to help the veteran, you have to help the people who are around the veteran as well.

LAS ENFERMEDADES MENTALES

(This document was developed by NAMI)

¿Qué son las enfermedades mentales?

Las enfermedades mentales son desordenes del cerebro que alteran la manera de pensar y de sentir de la persona afectada al igual que su estado de animo y su habilidad de relacionarse (identificarse) con otros. Tal como la diabetes es un trastorno del páncreas, las enfermedades mentales son trastornos del cerebro que una persona de afrontar las exigencias normales de la vida diaria. Todas las enfermedades mentales son causadas por desordenes químicos del cerebro.

En este país, cinco millones de personas tienen una enfermedad mental. Las enfermedades mentales pueden afectar a personas de cualquier edad, raza, religión o situación económica, Enfermedades no son el resultado de debilidades de la persona enferma, de una falta de carácter, o una mala educación.

Estas enfermedades son tratables. La mayoría de las personas que tienen una enfermedad mental necesitan medicamentos para ayudar a controlar los síntomas de la enfermedad. La ayuda de un consejero, los grupos de autoayuda, el acceso a una

vivienda adecuada la rehabilitación vocacional, ayuda económica y otros servicios de la comunidad pueden ofrecer el apoyo y la estabilidad necesarios para la recuperación de la persona que tiene una enfermedad mental.

DEPRESION SEVERA

Defección

La depresión es mucho más que un sentimiento transitorio de tristeza, es una enfermedad biológica. Sucesos negativos en la vida de un persona, tales como la pérdida de un ser querido o estrés crónico pueden desencadenar depresión severa. Debido a que las apariencias externas de una persona con depresión parecen se normales, a menudo la depresión se diagnostica incorrectamente i sencillamente no se diagnostica.

Síntomas

- Cambios en el patrón de sueño.
- Cambios en el apetito
- Disminución en la capacidad para concentrarse y tomar decisiones
- Pérdida de energía
- Pérdida de interés y placer en las actividades normales
- Baja autoestima
- Sentimientos de desesperanza
- A veces el síntoma principal no es el sentirse deprimido sino el tener malestares físicos como dolores de cabeza, problemas estomacales o dolores que no tienen una causa obvia.

Tratamiento y Recuperación

Existen muchos tipos de tratamiento para la depresión aguda, y la elección de uno de ellos depende del individuo y de cuan severos sean sus síntomas. En la mayoría de los casos, para obtener

un tratamiento eficaz se combinan los medicamentos con la psicoterapia.

Es posible que las personas que sufren episodios de depresión aguda, recurrentes necesiten seguir tomando los medicamentos necesarios para prevenir o aminorar futuros episodios.

El 80% de las personas con depresión severa pueden mejorar y tener una vida normal con la ayuda de un tratamiento continuo. Lo más importante es que las personas que tienen depresión aguda reciban un diagnóstico y tratamiento correcto y temprano.

TRASTORNO BIPOLAR (TRASTORNO MANIACO-DEPRESIVO)

Definición

Las personas que tienen trastorno bipolar experimentan periodos de extrema euforia (manía), y de extrema tristeza (depresión). Estos cambios intensos anormales pueden durar varios días, semanas o meses, y a menudo están separados por periodos de estados de ánimo normales.

Episodio maniaco: Síntomas

- Hiperactividad
- Temperamento explosivo
- Juicio disminuido
- Impulso exagerado de gastar dinero
- Aumento del impulso sexual
- Conducta agresiva
- Ideas grandiosas e ideas delirantes
- A medida que se intensifica la fluctuación del estado de ánimo, aumentan la pérdida del auto-control, la desorganización y la irritabilidad hasta que con el tiempo se pierde la capacidad de funcionar normalmente.
- Debido a la euforia que experimentan durante se fase maniaca, las personas

enfermas piensan que están mejor que nunca y, por lo tanto, no buscan ayuda profesional.

Episodio depresivo: Síntomas

- Perdida de interés o placer en las actividades usuales
- Tristeza profunda e irritabilidad
- Cambios en los patrones de sueño
- Perdida de apetito
- Dificultad para concentrarse
- Baja autoestima
- Pensamientos de suicidio

Tratamiento y Recuperación

Después del llegar a un diagnóstico acertado, entre un 80% y un 90% de los casos de personas con trastorno bipolar se pueden tratar exitosamente con medicamentos. El éxito del tratamiento también dependerá de la severidad del trastorno, de cuánto tiempo ha durado el padecimiento y de cómo responde el individuo a las intervenciones médicas y psicológicas.

Aunque el trastorno bipolar (maniaco-depresión) frecuentemente es un trastorno crónico o recurrente que requiere tratamiento continuo, casi todas las personas pueden lograr un alivio substancial de sus síntomas mediante las terapias adecuadas y pueden llevar una vida estable y satisfactoria.

ESQUIZOFRENIA

Definición

La esquizofrenia afecta la capacidad de una persona para:

- Pensar claramente
- Controlar sus emociones
- Tomar decisiones

Relacionarse con los demás una persona con esquizofrenia no tiene “doble personalidad.” La gran mayoría de las personas que padecen esta enfermedad no son peligrosas, aunque su comportamiento puede ser bastante impredecible. La esquizofrenia puede aparecer a cualquier edad, pero casi el 75% de las personas que tienen esquizofrenia tienen su primer episodio psicótico entre los 16 y 25 años. Esta enfermedad afecta más frecuentemente a los hombres que a las mujeres.

Síntomas

Alteración sensorial: Dificultad para interpretar las imágenes, sonidos, lenguaje y emociones cotidianas.

Alucinaciones, ideas delirantes y pensamientos confusos: Ver y oír cosas que no existen en la realidad (alucinaciones). Creencias fijas sobre asuntos obviamente falsos (ideas delirantes), por ejemplo, creer que se poseen poderes especiales.

Emociones alteradas O embotadas: Expresar sentimientos inapropiados o no expresar sentimiento alguno.

Tratamiento y Recuperación

Al igual que la diabetes, la esquizofrenia es un trastorno para el cual no se ha encontrado una cura, pero que si puede ser tratada y, en la mayoría de los casos, sus síntomas pueden ser controlados con medicamentos. Las terapias estructuradas que brindan información al paciente acerca de su enfermedad y como sobrellevarlas son de mucha utilidad. A menudo, es necesaria la hospitalización en las etapas iniciales de la esquizofrenia o durante recaídas severas, pero generalmente, una vez determinado el curso del tratamiento, se sustituye el hospital por servicios ambulatorios.

La gran mayoría de las personas con esquizofrenia pueden mejorar con los tratamientos disponibles actualmente, y las posibilidades para el futuro son muy prometedoras.

Y ahora, ¿Qué hago?

El sistema de salud mental puede ser difícil de entender. Si cree que usted o un ser querido podría tener síntomas de una enfermedad mental seria usted necesita ayuda profesional.

Durante una crisis

Si usted o un ser querido esta pasando por una crisis, debe entender que la emergencia puede ser peligrosa para usted o su ser querido y para las personas que estén a su alrededor. Si necesita ayuda inmediata:

- Puede ir a la sala de emergencias de un hospital o centro medico que ofrezca servicios psiquiátricos.
- Puede llamar a un centro o a una línea telefónica de ayuda para casos de crisis. Llame a 411 (información telefónica) para que le den un numero.
- También puede llamar al 911, si es una emergencia psiquiátrica.

No tenga miedo de hacer preguntas para entender perfectamente lo que significa que le admitan en un hospital psiquiátrico o a la unidad de psiquiatría de un hospital general. Asegúrese que entiende las respuestas alas siguientes preguntas:

- ¿Qué enfermedad tiene mi ser querido (o yo)?
- ¿Cuál es el tratamiento para esa enfermedad? ¿Quién ofrece el tratamiento?
- ¿Se puede dar tratamiento [ara esa enfermedad fuera de un hospital?

- Si me admiten o admiten a mi ser querido, ¿Cuánto tiempo cree que durara la estadía en el hospital?
- ¿Cómo podemos pagar por estos servicios?
- ¿Cómo puedo participar en el tratamiento de mi ser querido o en mi propio tratamiento?

SITIOS DONDE PUEDE OBTENER AYUDA EN CASOS QUE NO SON DE EMERGENCIA

En situaciones que todavía no son de emergencia, ¿En donde puede encontrar ayuda?

Busque información en el directorio telefónico a llame al 411 (información telefónica) si necesita ayuda para ponerse en contacto con los siguientes lugares:

- La división de salud mental del departamento de salud local.
- Otras organizaciones de salud mental de la comunidad.
- Agencias que ofrecen servicios a familias como instituciones católicas de ayuda (Catholic Charities) o centros que ofrecen servicios a familias.
- Asesores de escuelas o consultores sobre educación que recomiende la escuela de sus hijos.
- Asesores maritales y familiares.
- Asesores de orientación infantil.
- Un hospital psiquiátrico en su localidad.
- Un centro o una línea telefónica para casos de crisis.
- También tiene que tomar en consideración la importancia de tener un seguro de salud que cubra salud mental. Si tiene seguro, consulte a la compañía de seguro si cubre estos gastos. Si no tiene seguro, trata de conseguir un seguro que cubra salud mental.

Para mayor información sobre las enfermedades mentales o de cómo buscar ayuda, contacte a NAMI

a los teléfonos (703) 524-7600 or 800-950-NAMI (6264).

APPENDIX A

ACRONYMS & GLOSSARY OF TERMS

ADA – Americans with Disabilities Act

ADD – Attention Deficit Disorder

ADHD – Attention Deficit Hyperactivity Disorder

Affective Disorder – A psychiatric disorder characterized by extreme or prolonged disturbances of moods such as sadness, apathy, or elation. Two major groups are bipolar, or manic-depressive disorders, and unipolar disorders, such as depression.

Agoraphobia – Fear of being in public places; often accompanies a panic disorder.

Anorexia / Bulimia Nervosa – Anorexia Nervosa is an eating disorder that results in a weight of at least 15% below ideal body weight. An important component of Anorexia Nervosa is the refusal of the individual to maintain normal weight. Bulimia Nervosa is an eating disorder that results in binge eating. Frequently it is followed by purging or attempts to rid one's self of food through vomiting, taking laxatives, etc.

Anxiety Disorder – Characterized by excessive worry about everyday events; includes several disorders such as Generalized Anxiety Disorder and Obsessive-Compulsive Disorder.

Atypical medications – Newer antipsychotic medications that can sometimes relieve both the active and passive symptoms of some mental illnesses. Atypicals also appear to cause fewer side effects such as tremors or uncontrolled restlessness.

Bipolar Disorder – A biological disorder characterized by both manic and deep depressive episodes, with periods of recovery generally separating the mood swings. Psychosis may be present during manic or depressive episodes. Also known as manic depression.

CIT – Crisis Intervention Team; training for law enforcement officers.

CMHC – Community Mental Health Center

CMS – The Centers for Medicare and Medicaid Services is the government agency that manages both Medicare and Medicaid benefits.

Compulsion – An insistent, intrusive, and unwanted action that is repeated over and over.

Delusion – Fixed, irrational ideas not shared by others and not responding to reasoned argument.

ECT – Electroconvulsive Therapy – A procedure used for extremely severe cases of depression where an electric current is passed through the brain to produce controlled convulsions. This is not a common practice.

EPS – Extra-pyramidal Symptoms – Physical side effects of certain medications that can include tremors, slurred speech, anxiety and akathisia.

Hallucinations – Perceptions (sound, sight, smell, etc.) that occur without any external stimulus.

Mania – A mood disorder characterized by expansive, elation, talkativeness, hyperactivity, and excitability.

APPENDIX A (continued)

ACRONYMS & GLOSSARY OF TERMS

NAMI – National Alliance on Mental Illness

Obsession – Irrational thought, image, or idea that is irresistible and recurrent, if unwanted.

Obsessive Compulsive Disorder (OCD) – A major psychiatric disorder characterized by recurrent and persistent thoughts, images, or ideas that are intrusive and senseless (obsessions) and by repetitive, purposeful actions perceived as unnecessary (compulsion).

Panic Disorder – A psychiatric disorder characterized by sudden, inexplicable attacks of intense fear and body symptoms such as increased heart rate, profuse sweating, and difficulty breathing. Panic attacks occur twice a week on average. Antidepressants and anti-anxiety drugs, as well as psychotherapy, are used to treat panic disorder.

Paranoia – Suspiciousness not warranted by circumstances.

PTSD – Post Traumatic Stress Disorder -- PTSD is a mental health problem that can occur after a traumatic event like war, assault, or disaster.

Psychosis – A mental state characterized by impaired perception of reality, delusions, hallucinations, and distorted thinking. It can be associated with many psychiatric disorders.

SAMHSA – Substance Abuse and Mental Health Services Administration – a government agency that works to improve the quality and availability of substance abuse prevention, alcohol and drug addiction treatment, and mental health services.

Schizophrenia – A disease of the brain, the symptoms of which include thought disorders, delusions, hallucinations, apathy, and social withdrawal.

SSDI – Social Security Disability Income – for persons who are retired or disabled. Dependents may be eligible if diagnosed with a disability before the age of 22.

SSI – Supplementary Security Income – for indigent, disabled persons. SSDI and SSI are administered through the Social Security office.

Tardive Dyskinesia – A side effect of some anti-psychotic drugs, involving abnormal movements of the tongue, mouth, face, limbs and occasionally the entire body. It occurs in at least a mild form in 25 to 40 percent of patients on anti-psychotic drugs. The effects can be reversible.

Thought Disorder – Abnormalities including inability to concentrate or think in a logical sequence; rapid jumping between apparently unrelated thoughts.

Tourette's Disorder – A neurological disorder characterized by involuntary, rapid, and sudden

movements that occur repeatedly in the same way (tics). There also can be verbal tics, uncontrollable outbursts of sounds or words.

APPENDIX B

TELEPHONE REFERENCE GUIDE—NATIONAL AND FLORIDA AGENCIES

AIDS Hotline	800-342-2437
Department of Children and Families—Suncoast Region	813-558-5700
Depression and Bipolar Support Alliance-Florida	866-281-5322
Florida Child and Adult Abuse Hotline	800-962-2873 or 800-96A-BUSE
Florida Advocacy Center for Persons with Disabilities	800-342-0823
Florida Drug Assistance Helpline (Florida Legal Services)	800-436-6001
Florida Medicaid	888-419-3456
Florida Substance Abuse Hotline	800-729-6686
Florida Suicide Prevention Coalition	800-273-8255
Medicare	800-633-4227 or 800-MEDICARE
Medication Assistance Helpline	800-906-7279
National Alliance on Mental Illness (NAMI)	800-950-6264
National Alliance on Mental Illness--NAMI-Florida	877-626-4352
National Association for the Dually Diagnosed	800-331-5362
National Institute of Mental Health	866-615-6464
Social Security Administration	800-772-1213
State of Florida Information Center	866-693-6748
Treatment Advocacy Center	703-294-6001
Veteran's Assistance	800-827-1000

APPENDIX C

INTERNET RESOURCES

NAMI SARASOTA COUNTY – www.namisarasotacounty.org

American Psychiatric Association – www.psych.org

American Psychological Association – www.apa.org

National Association of Anorexia Nervosa and Associated Disorders – www.anad.org

Anxiety Disorders Association of America – www.adaa.org

Association of Black Psychologist – www.abpsi.org

Depression & Bipolar Support Alliance – www.ndmda.org

Depression & Bipolar Support Alliance – FL – www.geocities.com/dbsaflorida/dbsaflorida.html

Disabled People International – www.dpi.org

Florida Psychiatric Society – www.floridapsych.org

Florida Suicide Prevention – www.floridasuicideprevention.org

Institute of Psychiatry – www.iop.kcl.ac.uk

Medicaid – www.fdhc.state.fl.us/Medicaid

Medicare – www.medicare.gov

Mental Health America – www.nmha.org

Mental Health Consumers Survivors – www.lynx.org/csp

Mental Health Research Association – www.narsad.org

National Alliance on Mental Illness – www.nami.org

National Alliance on Mental Illness – Florida – www.namifl.org

National Institute of Mental Health – www.nimh.nih.gov

Social Security – www.ssa.gov

Substance Abuse & Mental Health Services Administration – www.samhsa.gov

United Way 211 Manasota – www.uw211manasota.net

The Advocacy Center for Persons with Disabilities (Florida) – www.advocacycenter.org

The Center for Substance Abuse Prevention – <http://prevention.samhsa.gov>

Treatment Advocacy Center (nationwide) – www.psychlaws.org

APPENDIX D RECOMMENDED BOOKS

Albers, L. et al -- *Handbook of Psychiatric Drugs, 2008 Edition*

Amador, Dr. Xavier – *I Am Not Sick, I Don't Need Help*

American Psychiatric Association – *Diagnostic and Statistical Manual of Mental Disorders*

Carter, R. and Golant, S. – *Helping Someone With A Mental Illness: A Compassionate Guide for Family, Friends and Caregivers*

Coon, D. and Mitterer, J.-- *Introduction to Psychology: Gateways to Mind and Behavior*

Cronkite, K. – *On The Edge of Darkness*

Duke, P. & Hockman, G. – *A Brilliant Madness*

Earley, P. – *Crazy: A Father's Search Through America's Mental Health Madness*

Faucett, J., et. al -- *New Hope for People with Bipolar Disorder 2nd Ed.: Authoritative Guide to the Latest in Traditional and Complementary Solutions*

Fine, C.-- *No Time to Say Goodbye: Surviving the Suicide of a Loved One*

Fuller, E. T. and Knable, M.-- *Surviving Schizophrenia: A Manual for Families*

Gorman, J.-- *The Essential Guide to Psychiatric Drugs, Revised and Updated*

Hallowell, E. and Ratey, J.-- *Driven to Distraction: Recognizing and Coping with Attention Deficit Hyperactivity Disorder (ADHD) Childhood through Adulthood*

Hyman, B. and Pedrick, C.-- *Obsessive Compulsive Disorder*

Jamison, K. R. – *The Unquiet Mind: A Memoir of Moods and Madness*

Mamannus, J.-- *Living Well With Depression and Bipolar Disorder:*

What Your Doctor Doesn't Tell You...That You Need to Know

Meuser, K. & Gingerich, S. – *The Complete Family Guide to Schizophrenia: Helping Your Loved One Get the Most Out of Life*

Miklowitz, D. and George, E. -- *The Bipolar Teen: What You Can Do to Help Your Child and Your Family*

Neugeboren, J. -- *Transforming Madness: New Lives for People Living with Mental Illness*

Papolos, D. & J. – *The Bipolar Child: The Definitive and Reassuring Guide to Childhood's Most Misunderstood Disorder 3rd Edition*

APPENDIX E

YOUR RIGHTS IN A FLORIDA MENTAL HEALTH FACILITY

An individual experiencing a mental health crisis can be admitted to a mental health facility. At the point of admission, the patient should be informed of his or her rights and should be able to ask questions and receive answers about those rights. Under federal law and Florida's Mental Health Act, your rights are protected as follows:

RIGHT TO INDIVIDUAL DIGNITY:

You are to be treated with dignity and respect at all times.

RIGHT TO COMMUNICATE:

You may talk with people you choose by local telephone or in person, unless determined to be harmful to you or others.

RIGHT TO QUALIFIED TREATMENT:

You are to receive treatment and services based upon your needs; and you are expected to participate in your treatment plan.

RIGHT TO BE SAFE:

You are to be free of restraint, seclusion, isolation, or emergency treatment orders. Laws prohibit neglect or abuse of persons in a facility; however, certain rights can be restricted by your doctor for safety reasons.

RIGHT TO POSSESS CLOTHING & PERSONAL EFFECTS

RIGHT TO RELEASE OR DISCHARGE:

You may request at any time, if you are on voluntary status. You will be released within 24-hours from community-based, receiving facility (or three days from a state facility), unless a petition is filed with the court to hold you for an involuntary placement hearing.

RIGHT TO EXPRESS AND INFORMED CONSENT:

You must be given the following information before you are asked to give consent to treatment: the reason for your admission, your proposed treatment and its purpose, common side-effects of your treatment and alternatives and the approximate length of care.

RIGHT TO AN ATTORNEY & REPRESENTATIVE:

You will have an attorney appointed to represent you if you are placed at a facility on involuntary basis. Most often this is a Public Defender.

RIGHT TO PRIVACY & CONFIDENTIALITY:

You will have privacy when talking with your doctor, team members and visitors whenever possible. Your treatment record is kept private except from your guardian, your attorney, certain state agencies, your parent or next-of-kin (limited information), or because of a court order or if you threaten to harm someone.

RIGHT TO VOTE

COMPLAINTS & GRIEVANCES: You can make a verbal or written complaint if you feel you or others are not treated fairly.

INVEST IN NAMI SARASOTA COUNTY TODAY!

If you found the information in the NAMI *Family Guide on Mental Illness* helpful, please consider investing in NAMI today. Through our mission of support, education, and advocacy, our goal is to continue to provide all NAMI programs and services at no charge to those who are affected by mental illness. We are the agency publishing this edition of the guide, but we get help distributing it to those who need it most through our community mental health and substance abuse systems.

Representatives from each of the social service agencies serve on the Sarasota County Mental Health and Substance Abuse Coalition, as we work together to develop and implement a continuum of services. Coalition agencies distribute the Guide to their family members, and NAMI also has the guide available at all our community events, health fairs, education programs, support groups and civic presentations.

NAMI Sarasota County Florida, Inc. is a charitable organization organized under 501 (c)(3) of the Federal Code, which gives the organization our non-profit status. The organization is supported by generous donations from individuals, businesses and community mental health providers. Programs and services are offered locally to those with a mental illness and their families and are offered free of charge so that cost does not become a barrier to obtaining help.

YES! I WOULD LIKE TO INVEST IN THE FUTURE OF NAMI SARASOTA COUNTY FLORIDA, INC.

NAME: _____

ADDRESS: _____

CITY: _____ STATE: _____ ZIP: _____

E-MAIL ADDRESS: _____

HOME PHONE: _____ OTHER PHONE: _____

ENCLOSED IS MY CONTRIBUTION OF \$ _____

Please make checks payable to NAMI SARASOTA COUNTY, INC.

Mail to: P. O. BOX 1741 | SARASOTA, FL | 34230

Or donate online at NAMI SaraostaCounty.org



BECOME A MEMBER OF NAMI TODAY!

Name: _____
(Title) (First) (Last)

Name of Organization: _____

Street Address: _____ Apt./Unit # _____

City/State/Zip _____

Phone _____ E-mail address: _____

Please check this box to give NAMI permission to send you notices via e-mail of events, programs, education courses, support groups and other activities. Please note: NAMI Sarasota County WILL NOT share this e-mail address with others.

INDIVIDUAL— \$ 35.00 **OR** OPEN DOOR--\$ 3.00 (for those with special financial circumstances)

Membership category: (Please check all that apply)

- Parent of Adult Child
- Parent of child under 18
- Sibling or Other Relative
- Spouse or Life Partner
- Friend
- Professional
- Provider
- Adult Child of person with mental illness
- Law Enforcement
- Consumer--Individual with mental illness
- Other _____

Interests / Reason for joining: (Please check all that apply)

- Family-to-Family
- Peer-to-Peer
- Family Support Group
- Education Programs
- Connection Recovery Support Group
- Provider
- CIT (for law enforcement)
- Other:



NAMI Sarasota County, Inc. is a non-profit corporation organized under section 501c(3) of the Internal Revenue Code (FIN 59-2464505). Contributions made to NAMI Sarasota County, Inc. are tax deductible to the fullest extent that the law allows. Our Florida state Charities registration number is CH 13932 under the Florida Dept. of Agriculture and Consumer Services Division. To view the official registration and financial information refer to www.freshfromflorida.com/Divisions-

Please make checks payable to:

NAMI SARASOTA COUNTY, INC.

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Sarasota, FL 34230

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