National Alliance on Mental Illness

PA, CUMBERLAND and PERRY COUNTIES NEWS

May 2014 **Volume XVII, Issue 5**

NAMI is the largest nationwide, grassroots membership organization devoted to improving the lives of those affected, directly and indirectly, by serious mental illness. NAMI is comprised of family members, friends and consumers.

Inside this issue:

Calendar:

May 15th—Support Meetings in Carlisle and New Cumb.
May 17th—NAMI PA C/P fundraiser at Hoss's
May 24th—MH Awareness event at Senators Game
May 31st—MH Awareness Concert at Little Buffalo State Park
June 5th—West Shore Support Grp
June 8th—NAMI Connections
June 9th—NAMI PA C/P Board Mtg
June 17th—Support Meetings in Carlisle and New Cumb.

Contact Us:

P.O. Box 527
Carlisle, PA 17013
http://www.namipacp.org
findhope@namipacp.org
Message line number:
240-8715

GET ON BOARD WITH THE MENTAL HEALTH MONTH EVENTS

On Saturday, May 17th NAMI PA C/P is joining with **Hoss's for a fundraising event**. If you dine at Hoss's that day at Hoss's in Upper Allen Township [beside Stauffers of Kissel Hill at 51 Gettysburg Pike, Mechanicsburg, PA] and you give a copy this page, NAMI PA C/P will receive a share of your bill.

Group #22172

On Saturday, May 24th, 4:30 to late evening there will be an outing for Mental Health Month to a **Harrisburg Senators Game** on City Island, Harrisburg. The Senators will play the Bowie Baysox. Tickets are $11 with $4 of each ticket being donated back to participating groups. This will be a great setting for us to build and strengthen relationships. Mark your calendar and send your order for tickets with a check to NAMI PA C/P, PO Box 527, Carlisle, PA 17013. Write "Baseball Tkts" on your check. Bring your whole family out to this event. We would like to have at least 20 NAMI members in attendance.

On Saturday, May 31st—Noon to 6 PM—Mental Health Awareness Month Concert will be held at Little Buffalo State Park, Newport, PA . This will be terrific entertainment with information tables, and another great opportunity to strengthen our family ties. Now that warm weather has finally arrived it is not too hard to imagine what a good time it will be to be in the park with musical entertainment.

When we gather together with new friends at events such as are listed here, we support each other and strengthen our voice when we speak about matters of importance to our community.

MAY MEETING

NAMI PA of CUMBERLAND and PERRY COUNTIES

THURSDAY, MAY 15, 2014 at S.T.A.R.

253 Penrose Place, Carlisle, Pa.

[See page 4 for directions]

7:00 —8:30 Support Meeting

Duplication and distribution of this Newsletter is made possible by the MH/IDD Board of Cumberland/Perry Counties

NAMI PA, Cumberland and Perry Counties
National Alliance on Mental Illness

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support

What: Support Group Meeting
When: Meets 3rd Thursday of each month
Location: STAR (253 Penrose Place Carlisle, PA 17013)
Time: 7:00 pm up to 9:00 pm there will be an educational program once each quarter [every 3 months]. Where there is an education program it shall run from 7:00 PM until 7:50 PM, and the support meeting shall follow at 8:00 PM.

May 15, 2014	7:00 PM to 8:30 PM—Support Meeting
June 19, 2014	7:00 PM to 8:30 PM—Support Meeting
July 17, 2014	7:00 PM Program—TBD 8:00 PM up to 9:00 PM—Support Meeting

WEST SHORE SUPPORT GROUP

Meets at 6:30 PM on the 1st Thursday of each month at St. Timothy's Lutheran Church, 4200 Carlisle Pike, Camp Hill, PA. There may be an education program 1x per quarter. Call Thom at 697-2602 for information.

June 5, 2014	6:30 to 8:00 PM—Support Meeting

NEW CUMBERLAND SUPPORT GROUP [from York County F2F Class

Meets at 6:30 on the third Thursday of the month at the New Life Church, 530 Big Springs Road, New Cumberland, PA. Contact Beverly Riggins at 717-979-0519 for more information.

May 15, 2015	6:30 to 8:00 PM—Support Meeting

DAUPHIN COUNTY SUPPORT GROUP [Assoc with NAMI PA Dauphin County]

Meets at 7:00 on the 3rd Monday of each month at the Epiphany Lutheran Church at 1100 Colonial Rd., Harrisburg, PA. Contact Marge Chapman at 574-0055 for more information.

May 19, 2014	6:30 to 8:00 PM—Support Meeting

What is Mental Illness: Mental Illness Facts

From www.nami.org

Mental illnesses are medical conditions that disrupt a person's thinking, feeling, mood, ability to relate to others and daily functioning. Just as diabetes is a disorder of the pancreas, mental illnesses are medical conditions that often result in a diminished capacity for coping with the ordinary demands of life.

Serious mental illnesses include major depression, schizophrenia, bipolar disorder, obsessive compulsive disorder (OCD), panic disorder, post traumatic stress disorder (PTSD) and borderline personality disorder. The good news about mental illness is that recovery is possible.

Mental illnesses can affect persons of any age, race, religion, or income. Mental illnesses are not the result of personal weakness, lack of character or poor upbringing. Mental illnesses are treatable. Most people diagnosed with a serious mental illness can experience relief from their symptoms by actively participating in an individual treatment plan.

In addition to medication treatment, psychosocial treatment such as cognitive behavioral therapy, interpersonal therapy, peer support groups and other community services can also be components of a treatment plan and that assist with recovery. The availability of transportation, diet, exercise, sleep, friends and meaningful paid or volunteer activities contribute to overall health and wellness, including mental illness recovery.

Here are some important facts about mental illness and recovery:

- Mental illnesses are serious medical illnesses. They cannot be overcome through "will power" and are not related to a person's "character" or intelligence. Mental illness falls along a continuum of severity. Even though mental illness is widespread in the population, the main burden of illness is concentrated in a much smaller proportion-about 6 percent, or 1 in 17 Americans-who live with a serious mental illness. The National Institute of Mental Health reports that One in four adults-approximately 57.7 million Americans-experience a mental health disorder in a given year
- The U.S. Surgeon General reports that 10 percent of children and adolescents in the United States suffer from serious emotional and mental disorders that cause significant functional impairment in their day-to-day lives at home, in school and with peers.
- The World Health Organization has reported that four of the 10 leading causes of disability in the US and other developed countries are mental disorders. By 2020, Major Depressive illness will be the leading cause of disability in the world for women and children.
- Mental illness usually strike individuals in the prime of their lives, often during adolescence and young adulthood. All ages are susceptible, but the young and the old are especially vulnerable.
- Without treatment the consequences of mental illness for the individual and society are staggering: unnecessary disability, unemployment, substance abuse, homelessness, inappropriate incarceration, suicide and wasted lives; The economic cost of untreated mental illness is more than 100 billion dollars each year in the United States.
- The best treatments for serious mental illnesses today are highly effective; between 70 and 90 percent of individuals have significant reduction of symptoms and improved quality of life with a combination of pharmacological and psychosocial treatments and supports.
- With appropriate effective medication and a wide range of services tailored to their needs, most people who live with serious mental illnesses can significantly reduce the impact of their illness and find a satisfying measure of achievement and independence. A key concept is to develop expertise in developing strategies to manage the illness process.
- Early identification and treatment is of vital importance; By ensuring access to the treatment and recovery supports that are proven effective, recovery is accelerated and the further harm related to the course of illness is minimized.
- Stigma erodes confidence that mental disorders are real, treatable health conditions. We have allowed stigma and a now unwarranted sense of hopelessness to erect attitudinal, structural and financial barriers to effective treatment and recovery. It is time to take these barriers down.

NAMI Connection

National Alliance on Mental Illness RECOVERY SUPPORT GROUP

"I've been there, I understand."

Connections is meeting at new day and time!!

NAMI Connection is a recovery self help support group for people living with mental illness.

WHEN: 2nd Sunday each month at 2:00 PM

WHERE: Aurora Cyber Café 104 West Main Street, Downtown Mechanicsburg, PA 17050 (717) 591-9598 (across from Jo Jo's Pizza)

WHO: Jen and Chris, NAMI National trained Support Facilitators

CONTACT: Any group related questions can be directed to Jennifer at (717)385-8028.

JOIN US FOR 2014

$35.00 For an individual

Membership includes membership in NAMI [national] and NAMI PA, and Subscriptions to The Advocate, The Alliance, and NAMI PA C/P News.

$35.00 For a Family

Same price as an individual. A family consists of two people living at the same address. A family has one vote, and will receive one copy of subscriptions.

$3 - $35.00 For "Open Door" membership

*Anybody can opt to join as an open door member. Dues are **any amount that can be afforded.** This option is available so that membership is not denied due to financial hardship. Open door members are regular members with all the privileges and powers of membership including all subscriptions.*

$50.00 For Professional Membership

A Professional member shows support for the mission and goals of the organization. Upon request, NAMI PA C/P will provide multiple copies of our newsletter for the waiting room of Professional Members.

Make Payment to:
NAMI PA C/P
Send Payment to: NAMI PA C/P
Box 527, Carlisle, Pa 17013

JOIN NOW TO BECOME PART OF THE NAMI FAMILY

Memberships submitted now will extend to the end of 2014

How To Get Low-Cost or Free Psychiatric Medications

Do you need help paying for psychiatric medications? There's an organization named Partnership for Prescription Assistance which may be able to help. The group, which counts almost every U.S. pharmaceutical company as a member, helps qualifying patients without prescription drug coverage get the medical and mental health medicines they need for free or nearly free. You can visit their website or call 1-888-477-2669 and learn whether you're eligible for a patient assistance program. A trained specialist will ask a series of short questions and help identify the right patient assistance program you.

Beware, there are lots of scam groups online which purport to do the same thing...for a fee. This is completely free and a legitimate source of help.

Website for Partnership for Prescription Assistance:
http://www.pparx.org/en

DIRECTIONS TO S.T.A.R.

From I-81:

- Take Hanover St. Exit and turn towards town, [Rt. 34 North]:
- At the major intersection at Noble Blvd, turn left on Noble Blvd.
- Proceed straight ahead at the first Stop sign at West St.;
- Turn right after the gas station on Penrose Pl.;
- The Penrose Plaza is immediately on your left;
- STAR is the last store front on the right end of the Plaza.

From Downtown Carlisle:

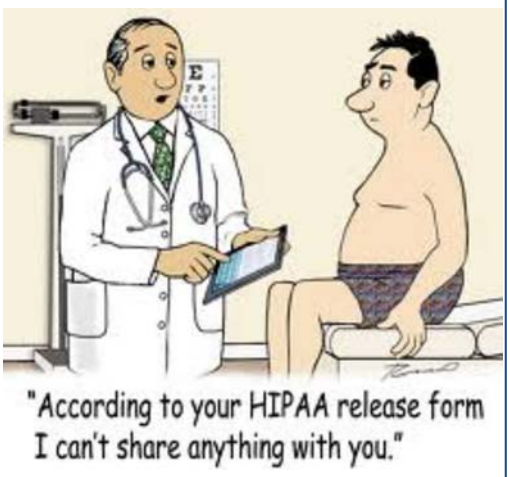
- Take Hanover St. out of town [Rt. 34 South].
- At the major intersection at Noble Blvd, turn right on Noble Blvd.
- Proceed straight ahead at the first Stop sign at West St.
- Turn right after the gas station on your right;
- The Penrose Plaza is immediately on your left;
- STAR is the last store front on the right end of the Plaza.

MEMBERSHIP RENEWALS

Please check your records to see if you have renewed your membership since October 1, 2013. If not, Please use the form on the last page of this newsletter to renew now. If you are unsure, renew now and if you had previously renewed we will regard your check as a donation.

New Federal Guidance Addresses HIPAA Hurdles

(Feb. 27, 2014) The US Department of Health and Human Services (HHS) this week issued new guidance intended to clarify when providers may share information related to a patient's mental health with family members and others.



While this guidance does not change the law it provides a great tool for families and caregivers by undercutting some of the excuses health providers use to withhold information from families dealing with psychiatric crisis.

The Health Insurance Portability and Accountability Act of 1996 (HIPAA) created a national standard for the protection of certain types of health care information. The US Department of Health and Human Services issued a "Privacy Rule" in 2002 to implement the requirements of HIPAA.

Most families who have dealt with serious mental illness are familiar with the hurdles this act and its rule can present when trying to get treatment for a loved one. ERs, hospitals, doctors, nurses and just about everyone else in the treatment stream routinely withhold critical health information on the basis of HIPAA.

However, in a House subcommittee hearing last spring examining whether HIPAA prevents people with severe mental illness from receiving timely and effective treatment and puts the public at risk as a result, testimony made it clear that HIPAA is being widely "misinterpreted and over interpreted" to create hurdles not authorized by the law. Representative Tim Murphy (R-Pennsylvania) subsequently included clarifications to HIPAA's use in his Helping Families in Mental Health Crisis Act, now pending in Congress.

The guidance appears to take aim at some of the overreaching Murphy's bill addresses. Among other points, the new clarifications address when HIPAA permits health care providers to:

- Communicate with a patient's family members, friends, or others involved in the patient's care;
- Communicate with family members when the patient is an adult;
- Consider the patient's capacity to agree or object to the sharing of their information;
- Involve a patient's family members, friends, or others in dealing with patient failures to adhere to medication or other therapy;
- Communicate with family members, law enforcement, or others when the patient presents a serious and imminent threat of harm to self or others.

The following information is from www.nami.org:

The Health Insurance Portability and Accountability Act (HIPAA) is a federal law that helps protect the privacy of individual health information. For individuals living with mental illness, this law is important, because it helps protect confidential mental health treatment records.

Over the years, however, there have been many misunderstandings about the type and range of information that mental health treatment providers are allowed to share with others. This often resulted in situations where family and friends of a person living with mental illness were unable to communicate with healthcare providers, often to the detriment of a loved one.

The federal Office of Civil Rights (OCR) at the Department of Health and Human Services (HHS) has enforcement authority over HIPAA. On Feb. 21, 2014, OCR released guidance clarifying how and when healthcare providers may share an individual's mental health treatment information with others. Open communication between a mental health provider and family members or friends of a person living with mental illness can help make sure that the individual receives the best treatment and care possible. Below is a set of questions and answers to make sure you know what HIPAA means for you.

Can healthcare providers share mental health treatment information to family members and friends of a person living with mental illness?

Yes, healthcare providers may share information about treatment with a person's family or friends if the person with mental illness does not object.

Are health care providers required to obtain a signed informed consent release before sharing information with family and friends?

(Continued on page 6)

(Continued from page 5)

No, citing the "integral role that family and friend's play in a patient's health care," OCR's guidance states that providers may ask for permission to share relevant information, may tell the person that they intend to discuss information and give him or her the chance to object, or may infer from the circumstances, using professional judgment, that the person does not object. For example, if a person receiving treatment invites a family member and friend to be present in a treatment situation, the provider may assume that the person does not object to disclosure of information.

What happens if the person living with mental illness objects to information sharing?

If the person receiving treatment is an adult, objects to the release of information, and is deemed capable of making healthcare decisions by the healthcare provider, then the healthcare provider may not share information with family or friends. If the healthcare provider determines that a person does not have the capacity to make healthcare decisions, then the provider may choose to share information with family, friends, or other individuals involved in the person's care if the provider believes it is in the person's best interest. A court order is not required for a determination that a person lacks capacity. Discretion lies with the treatment provider, based on professional judgment.

How much information can the healthcare provider share with a person's family members or friends?

Healthcare providers should exercise professional judgment and disclose only the information that is necessary or directly related to the family member or friend's involvement in care. Psychotherapy notes—notes that are written by a provider during counseling sessions detailing specific conversations—are treated differently than other healthcare information because they may contain especially private or sensitive information. In most instances, a provider must have a patient's permission before sharing information contained in psychotherapy notes.

May family members or friends communicate with a healthcare provider if they are worried about a person's health or wellbeing?

Yes, family members or friends may share information that they believe might be relevant or helpful to a treatment provider. Healthcare providers are not required to disclose this communication to the individual receiving treatment.

Can healthcare providers share information with parents or guardians of children?

Generally speaking, yes, a healthcare provider may share treatment information with a parent, guardian, or an individual acting as a personal representative for a child.

At what age is a child considered an adult for the purposes of healthcare decisions?

Generally, age 18, but HIPAA defers to state law if a state has a different standard.

Are there any other restrictions on how and when a healthcare provider may share information with parents or guardians?

HIPAA establishes a floor for the privacy of health information. State laws that are more protective of privacy supersede HIPAA. State laws vary and it is important to become familiar with the laws in your state.

In addition, there are some federal laws that may have additional restrictions on sharing treatment information with parents or guardians. For example, the federal confidentiality statute that applies to federally-funded drug and alcohol treatment programs has standards that are stricter than HIPAA.

Can healthcare providers share protected mental health information with law enforcement officials?

Yes, in certain circumstances, particularly if the person living with mental illness poses a danger to self or others, then healthcare providers may disclose necessary information.

Ask the Doctor: Teleconference Series

NAMI's *Ask the Doctor* teleconference is a monthly series hosted by NAMI's Medical Director, Dr. Ken Duckworth. Typically, he is joined by another mental health professional or advocate who in turn presents on a topic in his or her area of expertise. Each month, two such calls are hosted; one focuses on adult issues, the other on child and adolescent issues.

To access these calls, dial **1 (888) 858-6021 and enter pass code 309918#**. These calls are always held at *11 a.m. E.T. on scheduled dates unless otherwise noted*. The *Ask the Doctor* schedule and previously recorded podcasts can be found below.

Upcoming Ask the Doctor Schedule

Calls on adult issues

May 23, 2014: Dr. Kim Mueser; Psychiatric Rehabilitation
June 27, 2014: Dr. Don Goff; Schizophrenia
July 2014: No Call
August 22, 2014: Dr. John Oldham; Borderline Personality Disorder

Calls on child, adolescent and young adult issues

May 16, 2014: Dr. Sarvet; Mass.Child Psychiatry Access Project
June 20, 2014: Dr. Gabrielle Carlson; Changes to the DSM
July 2014: No Call

Rep. Murphy Introduces Bill to Overhaul Federal Mental Health System

BY LIZ REIDFOR WESA FM – PITTSBURGH'S NPR NEWS STATION

The federal government spends around $125 billion on mental health annually, but the ways in which that money is spent are ineffective and antiquated, according to U.S. Rep. Tim Murphy (R-Allegheny).

"The amount of money the federal government spends that they have no accountability for, the wasteful things that are done, the complete lack of demanding evidence based care," Murphy said during a mental health forum at Allegheny General Hospital Monday morning. "There was a recent report that came out in February (which found that) the Department of Defense (spent) over $100 million on their prevention programs, and they found it didn't make a difference."

Murphy is a clinical psychologist and a member of the Energy and Commerce Subcommittee on Oversight and Investigations. After a nearly year-long review of the country's mental health system, Murphy has introduced legislation that would overhaul the system. H.R. 3717, also known as the "Helping Families in Mental Health Crisis Act" is meant to provide fixes for what Murphy calls a lack of accountability, results-oriented research, and meaningful prevention.

Murphy said two of the main problems are that there is still a widespread stigma against people with mental illnesses, and that many people find it difficult to get treatment or even a diagnosis for mental illness until it's too late.

"Government has made it difficult to get help and said you can only get help if you're a danger," Murphy said. "The only time people really step in is if you're about to murder someone or murder yourself. People (with a mental illness) have this idea that 'Oh, they're just going to lock me up.' We need people to understand that these (mental illnesses) are diagnosable and they're treatable and the earlier we catch them the better."

Murphy proposes to catch, diagnose, and treat mental illnesses earlier by clarifying federal rules on doctors' ability to communicate with the family and caregivers of people suffering from mental illness. The bill would also increase access to acute care psychiatric beds in hospitals by tweaking Medicaid rules, promote alternatives to long-term inpatient care, advance telepsychiatry for underserved and rural populations, beef up evidence-based research requirements for federal grant funding, and integrate primary and behavioral health care. The bill would also make it easier for psychiatrists and other clinical healthcare professions to volunteer at community health clinics, which Murphy said is often stymied by federal legal barriers and the high cost of medical malpractice insurance.

Murphy said that between twenty and fifty percent of incarcerated persons struggle with mental illness, which puts a drain on the system and only exacerbates mental health issues.

Allegheny County District Attorney Stephen Zappala said many people could avoid incarceration with proper diagnosis and treatment, but that often families and caregivers do not know where to get help.

"I think that's a failure in and of itself that we have not provided enough information for those types of families, where they can help their son, daughter, husband, or wife before they get jammed up in the criminal justice system," Zappala said.

Both Zappala and Murphy were quick to point out that people with mental illnesses are far more likely to be the victims of violent crime than the perpetrators.

Murphy said there are several effective mental health prevention and research programs including the RAISE project, which stands for Recovery After an Initial Schizophrenia Episode and is taking place in more than twenty community health centers across the country.

Murphy also had praise for the Center for Traumatic Stress in Children and Adolescents, which provides evaluation and treatment for children and teenagers who experience child abuse and neglect, domestic or community violence, death of a family member, disaster, and other forms of trauma.

Murphy said that he doesn't currently have numbers on how much his proposed overhaul would cost the federal government, but he was confident that it would save the nation money in the long term.

"(Legislators) think if we just throwing money at existing programs that's all we need to do," Murphy said. "My point is that existing programs aren't working. That's why you're seeing increases in crime and victimization, homelessness, substance abuse. (These things) have all increased since we started putting money into this."

Murphy said the bill has received bi-partisan support and that Senate allies in favor of the legislation include Sen. Debbie Stabenow (D-Michigan), and Sen. Roy Blunt (R-Missouri). The bill was introduced in December 2013 and was referred to the House Subcommittee on Crime, Terrorism, Homeland Security, and Investigations in January.

For more information about this Bill, visit Congressman Murphy's website at:

http://murphy.house.gov/helpingfamiliesinmentalhealthcrisisact

About the First Episodes of Psychosis

Early identification and evaluation of the onset of psychosis is an important health concern. Early detection and intervention improve outcomes. Psychosis may be transient, intermittent, short-term or part of a longer-term psychiatric condition. It is important to understand the range of possibilities, both in terms of possible diagnosis associated with psychosis and the prospects for recovery. This NAMI website is a resource guide for your increased understanding of assessing, treating and living with new onset psychosis, including strategies to help the return to school, work and daily life.

What Is Psychosis?

Psychosis (psyche = mind, osis = illness) is defined as the experience of loss of contact with reality, and is not part of the person's cultural group belief system or experience. Psychosis typically involves one of two major experiences:

A. *Hallucinations* can take the form of auditory experiences (such as hearing voices); less commonly, visual experiences; or, more rarely, smelling things that others cannot perceive. The experience of hearing voices has been matched to increased activity in the auditory cortex of the brain through neuroimaging studies. While the experience of hearing voices is very real to the person experiencing it, it may be very confusing for a loved one to witness. The voices can often be critical (*i.e.* "you are fat and stupid") or even threatening. Voices also may be neutral (*i.e.* "the radio is on") and may involve people that are known or unknown to the person hearing the voices. The cultural context is also important. For example, in some Native American cultures, hearing the voice of a deceased relative is part of a healthy grieving process.

B. *Delusions* are fixed false beliefs. Delusions could take the shape of paranoia ("I am being chased by the FBI") or of mistaken identity (a young woman may say to her mother, "You are an imposter—not my mother"). What makes these beliefs delusional is that these beliefs do not change or modify when the person is presented with new ideas or facts. Thus, the beliefs remain fixed even when presented with contradicting information (the young woman continues to believe her mother is an imposter, even when presented with her mother's birth certificate and pictures of her mother holding her as a baby). Delusions often are associated with other cognitive issues such as problems with concentration, confused thinking and a sense that one's thoughts are blocked. These experiences can be short lived (*e.g.* after surgery or after sleep deprivation) or periodic (as when associated with a psychiatric condition or persistent like bipolar disorder or major depression).

Some typical and early warning signs of psychosis include

- Worrisome drop in grades or job performance;
- New trouble thinking clearly or concentrating;
- Suspiciousness/uneasiness with others;
- Decline in self-care or personal hygiene;
- Spending a lot more time alone than usual;
- Increased sensitivity to sights or sounds;
- Mistaking noises for voices;
- Unusual or overly intense new ideas; and
- Strange new feelings or having no feelings at all.

These signs are particularly important when they are new or have worsened in the last year and if the individual has a close relative that has experienced psychosis. Learn more about psychosis risks by visiting the Center for Early Detection, Assessment and Response to Risk.

Behavior and thought processes are often impacted by delusions or hallucinatory experiences. People experiencing new onset psychosis may report trouble organizing their thoughts, feeling as if they are dreaming while awake or wondering if their minds are playing tricks on them. Hallucinations can distract a person's attention and executive functioning (the ability to prioritize tasks and make decisions) may also be impacted. Agitation or withdrawal often accompanies these experiences, which can be experienced in a variety of ways but are often anxiety-provoking or terrifying. At times, people experience these altered perceptions of reality with indifference or resignation, or they simply "fall into" the psychosis and lose interest in external reality. Shame and humiliation of being different often complicate the experience and make getting help more difficult.

Is Psychosis a Diagnosis?

No. Psychosis is like feverï¿½a very important symptom. When a person has a fever, it could be from a virus in the respiratory system or a bacterial infection of the urinary tract. These are two very different causes of fever and each cause requires different treatments. The reduction of fever is one way to know the condition has been addressed properly.

While we understand less about the three-pound "university" that is the human brain than we do about infectious disease, the same broad principles apply. The goal of a comprehensive evaluation is to determine if there is an underlying, reversible medical cause of the condition and if there is none to determine the psychiatric diagnosis. After the symptoms, the associated history and relevant workup have been put into a diagnostic framework, the next step is to develop a collaborative and com-

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prehensive plan with the person to address the symptoms in the context of this diagnosis. A comprehensive plan attends to the person interests and strengths and looks to school, work and relationships as the person's goals dictate.

What Is a First Episode of Psychosis?

A first episode of psychosis is the first time a person experiences a psychotic episode. The first such episode often is very frightening, confusing and distressing, particularly because it is an unfamiliar experience. Unfortunately, there are also many negative stereotypes and misconceptions associated with psychosis that can further add to this distress. You are not alone if you are having this experience (estimates place the risk of psychosis at about three in 100. Help is out there both for the individual and the family, and this help comes in many forms. By exploring NAMI'S web resource, you are already looking at the issue and seeing how your resilience and coping strategies can be employed to best deal with psychosis.

Psychosis is treatable. Many people recover from a first episode of psychosis and never experience another psychotic episode. Finding support and resources is essential to managing the experience, whether it is short-lived or lasts a good deal longer. NAMI has more than 1,000 locations across the country, made up of individuals and their families who help each other successfully live with serious psychiatric illnesses. We are here to help you and the people who love you.

Early Onset of Psychosis

When young children report hallucinations in the context of poor school performance social withdrawal or exhibit other odd behaviors then a diagnostic evaluation is required. The caregiver will assess the child, perform laboratory tests and may request developmental or psychological testing to help make a diagnosis. This could include neurologic problems, bipolar disorder, or childhood schizophrenia, which is a rare, but real, presentation.

Schizophrenia typically occurs in a window of the mid- to late-teens to the early 30s (this age range is a few year later for females, often the presentation is early- to mid-20s as opposed to the teen years). Symptoms of schizophrenia in school-age children are rare, and this is unexpected and traumatic for the family while they are seeking help and assessment. As this is an uncommon condition, local caregivers may struggle to put together a comprehensive plan. A teaching hospital with a department of child and adolescent psychiatry would be a good place to begin.

The National Institute of Mental Health (NIMH) has a research and clinical service center in Bethesda, Md., to better understand childhood schizophrenia, while providing state-of-the-art care to children in care. This program offers diagnostic and treatment options to children who have had the onset of psychosis prior to the age of 13. Children aged 6-18 are eligible to enroll.

Young Adults and New Onset Psychosis

Young adults are the most common age group to be at risk for their first episode of psychosis. The experience of psychosis impacts young adults at a developmentally vulnerable time. This is a stage of life that usually challenges young people to develop more independence, establish an identity, create intimate relationships and move away from the nest of the family home. Typically, young adulthood focuses on the external world and friends, while parents often serve a valuable—but less central—day-to-day role. Yet, if a young adult is having problems organizing his or her thinking or is distracted by hearing voices, functioning at a high level of independence will be problematic in many cases. Psychosis often impacts individuals in college years, and the culture in a college setting is not typically geared towards seeking help. Having a psychotic process separates the individual from peers and can impair social connections. The loss, or threat of loss, of social contacts adds stress to the person experiencing these symptoms. It is often scary and activates feeling of shame when one is having these experiences that are so difficult to discuss. This leads to isolation and may reinforce the power of the inner experience as withdrawal from external contacts occurs.

With a young adult away at college, parents may think they are supposed to keep some distance in order to support independence in a college-age child, and may not have adequate information in order to appreciate the onset of psychosis. Psychosis requires intervention as soon as the person or the family realizes the seriousness of the situation. University counseling centers are increasingly aware of the need to get support and assessment to students experiencing this challenge.

Young adults and families can be encouraged by the development of resources intended to help meet their unique needs. NAMI offers some resources, including NAMI on Campus, NAMI groups on some college campuses, and StrengthofUs.org, a social networking site specifically for young adults living with mental health conditions. These both offer young adults access to information and peer support from other young adults with a shared experience.

Later-in-life New Onset Psychosis

When the first presentation of psychosis is over age 40, this presentation raises the need for intensive medical evaluation. The probability that there is a detectable medical cause of psychosis increases with age, with increased use of medications, medical illness and surgical procedures. Delirium, which can present with psychosis (coupled with change in level of consciousness), is common in individuals who have other risks (*i.e.,* post-surgery, on multiple medications) or neurologic vulnerabilities (*e.g.* dementia, Parkinson's disease, cognitive decline). Multiple neurologic and medical conditions can present with psychosis later in life, and many of these are reversible.

Short-term Psychosis

A brief psychotic disorder that lasts between one day and one month and is typically associated with severe stress or the post-

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partum phase is considered short-term. The return to a nonpsychotic state is common in the condition.

Trauma and Its Relationship to Psychosis

Traumatic events impact body, spirit and brain. Research has demonstrated biological as well as psychological effects of traumatic events. The type of trauma as well as the developmental stage of the person and their brain also makes a difference in terms of how a traumatic event may manifest in the person's experience. The field of mental health has moved towards a more sophisticated understanding of how traumatic events can influence a person's experience, and a movement towards trauma informed care has been a focus of SAMSHA for years. This is an important departure as NAMI was founded in part by mothers who were falsely blamed for the neglect and reason their children had developed schizophrenia. The "schizophrenogenic mother" theory posited that cold and neglectful parenting caused schizophrenia. This "one size fits all" conceptualization blamed mothers and did not rely on empiric evidence. The relationship of traumatic event—of all kinds—and the development of psychiatric illnesses is emerging and reveals a significantly more complex story. We now know that the brain is plastic—it responds to its environment and that the way that environmental experiences manifests in a given person with their genetic makeup remains an important area of inquiry.

The Adverse Childhood Experience (ACE) study demonstrated a relationship between self reported adverse childhood experiences and multiple adult health problems, spanning both physical and mental health concerns. The researches noted higher rates of many health problems that correlate with the number of adverse childhood experiences in a large HMO population, including heart disease, lung disease, hypertension and mental health concerns including suicide. ACE were not limited to a few of the subjects followed---more than one fourth of individuals were exposed to substance abuse in the home and over two thirds of the sample reported at least one adverse experience. One individual in 10 had more than five adverse experiences and this population had more health concerns of all kinds later in life. Traumas impacted both health outcomes and also adult life choices—including substance abuse, domestic violence and sexually transmitted diseases. This is a powerful and provocative study and promotes more research in this area.

There is no simple *if A then B* in this compelling area of inquiry. Neurodevelopmental conditions like psychosis have many possible influences than span genetic, stress and environmental aspects. It does appear that adverse experiences are more common in people with psychotic disorders, yet a trauma history is not present in many individuals with psychotic disorders. In a review of two large data sets researchers found a relationship between multiple adverse experiencing and the later development of psychosis. "Experiencing two or more traumas significantly predicted psychosis and there appeared to be a dose response relationship."

For more on this research review, visit "Cumulative Traumas and Psychosis: An Analysis of the National Co morbidity Survey and the British Psychiatric Morbidity Survey" Shevlin *et al.*, *Schizophrenia Bulletin* 2008 34 (1).

The experience of psychosis can also be experienced as traumatic. The experiences can have many manifestations but terror and fear are key elements of traumatic experiences and these are common responses to the onset of psychosis. As the field goes forward, integrating awareness of the interaction of experience on brain and body development will improve approaches to individuals experiencing psychosis.

Causes of Psychosis

Risk Factors

When it comes to psychosis, the interplay between genetics and the environment is not yet fully understood. Researchers are continuing to explore the underlying genetic risks associated with psychosis. Research suggests that a wide range of environmental factors (such as birth injury, severe stress, sleep deprivation, maternal infection in the second trimester, head trauma and substance use) may trigger an underlying genetic risk and lead to an episode of psychosis. There is no one gene or stress that causes psychosis. Like asthma and diabetes, vulnerability to psychosis likely is the interplay of genetic risk and environmental factors. Much more needs to be understood about this interplay. The mapping of the human genome in 2003 begins what promises to be a long and challenging process to better understand the relationship between genetics, the environment and mental illness.

Of the many conditions that have psychosis as a symptom, schizophrenia is the best-studied in terms of the interplay between genes and environment. For example, using careful population records in Europe, researchers have shown the relative correlations of how the condition travels in families. Having first-degree relatives (parents, siblings) with schizophrenia increases your risk of having schizophrenia. For example, if you have an identical twin that was diagnosed with schizophrenia, your overall risk would be in the range of 50 percent. If you have a parent with the condition, you would have about a 10 percent chance of developing the disorder. These are probabilities only, as there have been no developments in determining any one person's risk with scientific precision.

There exists no single gene test for illnesses associated with psychosis, such as schizophrenia. There is evidence that vulnerability to psychosis may be increased in individuals who have a gene variant and who also smoke marijuana. It is best to avoid this substance, especially if you have any risk factors for development of psychosis.

Early Warning Signs

For some psychiatric conditions that later develop psychosis symptoms, there is often a prodromal (early) phase. In this

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THE VALUE OF FAMILY SUPPORT

By Jerry Malugeon

When it comes to helping someone in recovery from a mental illness, I am applying a broad definition to the class we commonly label *family.* For the purposes of this article, family includes relatives, significant others, close friends, various counselors, colleagues, peers and anyone else regularly engaged in supporting a loved one who is somewhere in his or her recovery process.

A great amount of research shows that individuals in a treatment program experience far better outcomes when supportive family members are involved in the recovery process. The ongoing participation of a family member may actually have a significant influence on whether a loved one achieves, at best, a stage of mere stability or actually learns to thrive within a health-filled state of progressive, meaningful recovery. When families play an essential role in planning and carrying out those treatment plans, hospitalizations and relapse rates are lower. Doctors in greater numbers are declaring that the involvement of family may well be one of the most important factors in whether a person recovers or not, as well as how much they recover.

An informed family is a more effective family, and since its role can be a complex and unique one its members need to learn how to appropriately participate in assisting a loved one achieve his or her recovery goals. They'll need to be well acquainted with these areas:

- Aspects of their loved one's illness, learning about its symptoms and recognizing the warning signs that can lead to relapse.
- Tools for supporting treatment goals, what they are and how to use them.
- Knowing what will help your loved one.
- Knowing what won't help.
- Importance of staying with a treatment program that promotes progressive recovery.
- Self-care.
- The necessity of always expecting recovery.

There are many communities that have groups to help families learn about these disorders and how to help individuals challenged by them. Perhaps one group has the most established family education program available, and that is the National Alliance on Mental Illness (NAMI), which has their Family-to-Family courses meeting throughout the country. More can be learned about these programs by calling (800) 950-NAMI or contacting http://www.nami.org.

Everyone with a brain illness should have an idea of what their own recovery will look like, and every family should help their loved one achieve that recovery.

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phase, the following may be noted:

Isolation and withdrawal

Loss of interest in peers

Declining self-care/hygiene

Change in thought pattern including disorganized thinking

Preoccupations/paranoid thinking

Lack of motivation

Getting a comprehensive assessment of these symptoms is important to understand the possible explanations for the change in the personï¿½s behavior.

Substance Use

For many individuals, the use of substances increases the risk of developing psychosis. In general, the younger the person and their developing brain are, the greater the risk posed by the use of substances.

Substances known to have links to possible psychosis include:

Marijuana/hash/THC

Methamphetamine *(including crystal meth)*

PCP/Psilocybin/Peyote /Mescaline

LSD

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