



Greetings on behalf of the Peer Advisory Committee

Welcome to this issue of "I AM NAMI". Have you ever been told: "You don't have any type of mental illness, you're just lazy!" "There is no such thing as mental illness, you're just wanting attention!" You don't have a mental illness, you're just trying to get out of holding a job!; or my very personal favorite oxymoron statement-mental illness, hah, "you don't have a mental illness, it's just in your head".

Check our website for
more information at
www.namistl.org,
or give us a call at
314-962-4670.

When you tell someone you feel you can trust that you have a mental illness do they talk down to you? Do they think you have lost all signs of intelligence? Do they think you have more than one personality? These are just a few of the stigmas that society believes or has been taught about mental illness, but in this issue you can read testimonies and articles that we hope will change the stigmas on mental illness. So to those who live around us, in our house, our communities and worldwide, we have mental illness- it doesn't have us-and with good coping skills, we are not hopeless; there is hope and healing and a whole lot of life in our living.

"Never give up on someone with a mental illness. When "I" is replaced by "we" illness becomes wellness." Shannon L. Alder

Speaking of wellness that brings to mind two events that I want to share with everyone in the NAMI St. Louis calendar. First is our **NAMIWalk on Saturday May 28, 2016** in Forest Park at the Upper Munny parking lot. So think about going on our website (<http://www.namistl.org/namiwalks.html>) to form a team, enter our team t-shirt contest, or just register as a single person. You can also register that day. Our walk is so important, not only to support NAMI and its mission and tasks, but we must also support one another in the mental health community and as advocates we need to be recognized. So also invite your legislators.

The second calendar reminder is our **annual Respect Award** presented at our annual NAMI business meeting in July. Is there a mental health professional that has made a difference in your life? Why not give them the recognition they really deserve by submitting their name on the form in the newsletter and sending it in to the office (address on the last page). Our NAMI St. Louis Advisory Committee will vote on all entered submissions. So think long and hard about who has been supportive and made a difference in your life.

"Once I knew darkness and stillness...My life was without past or future...but a little word from the fingers of another fell into my hand that clutched at emptiness, and my heart leaped to the rapture of living." Helen Keller

Well, I'm wishing all of you peace, blessings and good health. So chow for now!

Christopher Lee
NAMI St. Louis Peer Advisory Committee



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Tardive Dyskinesia

By Joanie Milligan

There are various types of medications taken by people with mental health issues and there may be many side effects. One of the side effects is tardive dyskinesia (TD), a movement disorder. TD can occur in the face of some of the symptoms are sticking out the tongue, blinking eyes, lip smacking, grunting, frowning and chewing. It can also effect the body such as foot tapping, swaying side to side, and the movements may be slow or fast. It can make it hard to work or stay active.

Your chances of getting TD go up the longer you are on antipsychotic medications. You are more likely to get TD if you are over 55 years old, have gone through menopause, or abuse alcohol or drugs. There are medicines to counteract TD.

One way to prevent TD is early intervention to stop the drug causing it, if possible. Whatever happens don't give up and be patient with yourself. Each person has to decide the benefits of taking medication, but talk to your doctor and do not stop psychiatric medications on your own.

For more information go to <http://www.namistl.org/fact-sheets.html>. There is a checklist to review symptoms and other helpful information.

Navigating Through the Stigma

By Ellen Fein Rosenbaum

Understand your own particular mental illness. I believe that is the lesson one needs to learn when mental illness enters into one's life. When mental illness is a daily reminder that we are not the same as we were before.

Getting over the stigma. The shame. The labels. The ignorance. Misunderstanding. Lack of trust. The stereotypes. The changes of behavior. The changes in thinking. Hospitalizations. Medications. Psychiatrists. Therapists. Losing Friends. Homelessness. Fear of our illnesses. Fear of losing control.

Learning to Take care of ourselves. Finding ourselves. Learning acceptance. No shame. Creating a full, satisfying life. Not worrying what others think. Feeling good about ourselves. Hitting the stigma right in the eye. These are some of the keys to getting past the stigma.

Tell yourself and tell the world, "I am not crazy. I have a chemical unbalance of the brain. I will not let it take over me. I will be strong and I will live with it the best way I can. I may not be the same as I was before this illness approached me, however, I can still feel good about who I am."

Stigma, shame...that is the poisonous part of mental illness.

The serum to stigma: Understanding. Acceptance. Healthy mind. Healthy body. You owe it to yourself to be the best "you" you can be.



MENTAL HEALTH
AWARENESS MONTH KICKOFF
A Day At The Theatre

TWISTED MELODIES

APRIL 20-MAY 1 BY KELVIN ROSTON JR.



APRIL 23
3:00 PM

EDISON THEATER AT WASHINGTON UNIVERSITY

THROUGH THE MIND OF MUSICAL GENIUS

DONNY HATHAWAY

Twisted Melodies is a fictionalized journey through the mind of musical genius Donny Hathaway. We see a man lost in space and time, battling schizophrenia and trying to come to terms with life.

Join us to witness the powerful and intense portrayal of the renowned jazz, blues and soul singer, composer and songwriter.

"It's rich, complex, beautiful."

-Jonathan Abarbanel, Windy City Times

TICKETS \$30

PERFORMANCE & POST SHOW DISCUSSION

with Writer/Performer, Kelvin Roston Jr. & Mental Health Professionals & Consumers

MORE INFO & TICKETS: theblackrep.org
314.534.3807



PARTNERING ORGANIZATIONS:



Myrtle Hilliard Davis
Comprehensive Health Centers, Inc.



To Tell or Not To Tell

I wanted to write an article on the STIGMA of mental illness in my life but I want to remain anonymous. The reluctance to write my name down at the end of this article is a direct result of the STIGMA I still feel about my bipolar disease after 50 years.

When I was 19 years old, I was in a foreign land when I experienced my first major depression and severe anxiety. Since I was in a student abroad program, the leaders of the group said I should go into the hospital. I was very scared for I did not know what was happening to me. I staying in the hospital for two weeks. Meanwhile my uncle in St. Louis found out I was in the hospital. A friend of his, who lived in the country where I was, came looking for me and discovered I was hospitalized. He told my uncle who was a doctor from the old county. My uncle wrote me a letter which said I should not tell anyone I was in the psychiatric ward in the hospital, because of what other people would think. He said to say I had a physical illness.

When I returned to St. Louis I did not even tell my parents I was hospitalized. They knew something was wrong with me for I started seeing a psychiatrist at the college's student health service. I was prescribed medication which immediately helped my depression. I was very fortunate, but I never discussed it with anyone- not even my family. My brother had already been suffering from catatonia/severe depression. We already felt very embarrassed about this and felt the community would stigmatize us. My parents and I had no one to talk to. There was no NAMI Family-to-Family program. My brother did not have a support program like the Independence Center to go to.

I worked for over 40 years with my illness. During my career, I never talked to my colleagues about my depression except for those who became my close friends. Even then, it was difficult to share with my friends not knowing whether they would reject me or not. I was embarrassed and ashamed to reveal this part of me.

I was thirty when I had a major depressive episode and put myself in the hospital. I called my boss and told her I would not be in on Monday for I was hospitalized for depression. She told me to try to come in anyway. I left the hospital with the help of close friends and returned to work that **Monday**. It was the hardest thing I had to do.

My boss was the only one who knew what happened. She gave me small repetitive jobs which I was able to do. I did not do my regular work. My co-workers knew something was wrong with me but nothing was said about it. I felt they were now treating me differently. I knew my life depended on keeping my job for I had to support myself. Going back to my family would only make things worse. I have been in therapy most of my life and would hide this too.

Although I have been embarrassed over my life time and felt the stigma of my illness, in the last few years, I have had the courage to speak about my family and myself. The first time was when I went to an open forum on physical and mental disabilities. The woman, who is now a very close friend, told her life story and how mental illness affected her. Because of her courage, I stood up in the audience after the talk and talked about my family and myself. After the forum closed, people gave me such positive feedback for telling my story also. I talked at a NAMI event a couple of years ago. I also spoke at my synagogue to raise awareness.

Stigma made me ashamed of myself. I was always worried my depression would show too much and people would know about me. I often felt isolated because of stigma. Now I feel connected to people who have mental illness and they also talk about it. I learned from them that it was okay to tell people I lived with bipolar disease. I no longer feel isolated, because people know who I am. I learned also that I am much more than my illness.

Although I will tell my story in public, I still do not want my name in print. Hence, stigma has not left me completely.

I hope this article will help you begin to talk about your mental illness and feel less stigma.

Anonymous

The Power of Stigma

By Sharon Lyons

“Advocates and experts who spoke with USA TODAY for an article on mental health described a system in shambles, starved of funding while neglecting millions of people across the country each year.” Strong words were used in a 2014 series tell a story that many in the mental health community know all too well.

Stigma, which the dictionary defines as a mark of disgrace or a strong feeling of disapproval, hurts. It hurts on the level of the individual and on the level of the community and the system. It leads to insensitive remarks about “crazy” people and to trauma and loss. Mental illness is traumatic for those diagnosed and their family members; and nearly everyone with mental illness experiences losses including relationships, self-esteem, employment, and education opportunities. Stigma has led to a separate and unequal system of mental healthcare that doesn’t serve those in need very well.

Stigma is a stubborn problem. One would think that education would be the solution. That once people had the facts about mental illness, the stigma would be eliminated, but not so. Studies have shown, for example, that stigma correlating violence and mental illness persists despite education.

What are we, advocates, to do?

We can start a movement! I believe we must first address self-stigma-that tendency to feel bad about ourselves. If we don’t feel positive about ourselves, how can we get others to feel positive about us and our treatment? We can look back to other movements, such as the 1960’s civil rights movement, for examples. In the 1960’s black people began to say “black is beautiful”, among other things, to increase self-love and positive images of themselves. Black people began to demand and get certain rights as a result of their movement.

We can speak out with righteous anger about discrimination and the lack of housing and services. I know this is scary for people with mental illness. We fear that if we get too emotional some may think we need more medication. But who better to speak up and tell our stories than us?

Injustice anywhere is a threat to justice everywhere.
-Martin Luther King Jr





NAMI St. Louis 2016 Respect Award

NAMI St. Louis established the Respect Awards in 2009 to honor professionals who have gone above and beyond their usual responsibilities to serve those with a mental illness. Two Award Categories: Outstanding Mental Health Individual Worker and Outstanding Mental Health Agency/Organization. Nominations must be from individuals with mental illness or their family members. Nominations must be from the person or family member of a person who has received services from the individual or organization. Nominees for the individual award should have at least 5 years work experience in the mental health field. Nominees must meet at least 5 of 10 criteria below.

NOMINATIONS ARE DUE BY JUNE 3, 2016. The selection committee will be comprised of mental health consumers and the family members of people with mental illness. The awards will be presented at the NAMI St. Louis Annual Meeting held in July.

Return nominations to: NAMI St. Louis, 1750 S. Brentwood Blvd, Ste 511, St. Louis, MO 63144, or by fax 314-962-4678, or email Sharon@namistl.org.

NOMINATOR

NAME _____ Address _____

City _____ State _____ Zip _____

Phone _____ Email _____

I am: A consumer of mental health services/person with a mental illness A family member of an individual with mental illness.

I NOMINATE: Outstanding Individual Organization _____

CRITERIA (PLEASE ANSWER QUESTIONS USING A SEPARATE PIECE OF PAPER, PROVIDING SPECIFIC EXAMPLES)

1. How does the person or organization establish trusting relationships where the consumer and mental health provider trust one another?
2. How does the person or organization maintain current and accurate knowledge of mental illness, treatments, and resources?
3. How does the person or organization acknowledge that mental illness is a common human occurrence, and as such treats people with mental illness with dignity given those with other illnesses?
4. In what way does the person or organization advocate for public policies that improve the lives of people with mental illness?
5. How is the person or organization responsible for physical, social, spiritual, and cultural needs of the consumer?
6. How does the person or organization include family, friends, and/or other providers in treatment planning, treatment, and follow-up?
7. In what ways does the person or organization demonstrate that the best interest of the consumer is a priority when making decisions?
8. Provide examples of how non-stigmatizing, person-first language is used when referring to people with mental illness.
9. Provide examples of the individual's involvement in activities outside their workplace that advances community mental health.
10. How does the person or organization go above and beyond their job description and usual work to help clients?

I AM NAMI Remembers Patty Duke (1946-2016)

Mental health advocate, Patty Duke, died on March 29, 2016. She won an Oscar for her performance as a young Helen Keller in “The Miracle Worker” in 1963.

Duke was diagnosed with bipolar disorder in 1982 after years of struggling with mood swings. She went public in 1987. She was featured in BP Magazine, a monthly publication on the disorder and Duke wrote her autobiography, “Call Me Anna” and coauthored “A Brilliant Madness” detailing her experiences including using alcohol to self-medicate.

Duke wrote: “What I’m realizing through this endeavor is that the saddest part of it is that the [answer] is really simple. It is the stigma that’s ingrained in us that keeps us from going to that simple solution,” she says, talking about the medication. “We have to keep beating it [the stigma] with that stick and never give up.”

No stranger to NAMI, Duke was awarded the Lionel Aldridge Award (NAMI’s highest consumer award) in 2006, and that year she also served as Honorary Chair of the NAMI Research Gala and attended the event to present an award to scientist Dr. Charles L. Bowden, whose work focused on bipolar disorder.

R.I.P. Anna.

SAVE THE DATE!!



National Alliance on Mental Illness

Saturday, May 28, 2016

**Upper Muny Parking Lot
In Forest Park**

For more information contact Deanna Orf,
by phone 314-962-4670
or email deannaorf@namistl.org

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Newsletter Mission:

The newsletter, established by the NAMI St. Louis Consumer Advisory Committee, will tell the stories of individuals with mental illness who are doing interesting things. It is a forum for information, inspiration, and creative expression.

Publication Guidelines

- Materials should be from individuals living with mental illness in the St. Louis area, unless invited by the Consumer Advisory Committee.
- In an attempt to decrease stigma and isolation that often accompany mental illness, we ask that you identify yourself by providing your name, address, and either phone number or email address. You will be contacted if there are questions about your material. You will also be contacted if your material or question is published. Names will be published, but no other identifying information will be made public.
- Items for publication should be free from profanity or language that is prejudicial toward any culture, race, religion, gender, type of mental illness, or type of disability.
- Submission does not guarantee publication. Items are published at the discretion of the Consumer Advisory Committee.
- Please keep stories, articles, and poetry to two pages or less. Please do not send originals as they will not be returned.
- Submissions may be made by email, U.S. Mail, or fax.

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