

# Brain Storm

## Our Mission

NAMI Tri-Valley, in collaboration with other community agencies and organizations, is dedicated to improving the quality of life for those whose lives are affected by mental illness, by providing support, resource information, education programs, and advocacy.

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## Caring for a Loved One with Serious Mental Illness Takes its Toll

**Elizabeth Sinclair**, Research Associate – Treatment Advocacy Center

Enormous levels of distress are felt by caregivers of individuals with serious mental illness, the majority of whom are family members of loved ones with the illness.

New research published by Debra Lerner, Lisa Dixon, and colleagues corroborates the feelings of many family members with a loved one with a serious psychiatric disease—caring for someone with serious mental illness takes its toll.

The study authors surveyed 1,398 eligible caregivers of individuals with serious mental illness that they contacted through advertisements sent to caregiver groups, the National Alliance on Mental Illness (NAMI), Schizophrenia and Related Disorders Alliance of America (SARDAA), the *Dear Abby* column, and others. The survey inquired about a range of concerns, including the amount of coping resources at their disposal, the resource demands on the caregiver, and the amount of stress they perceived.

### Study findings

Psychological distress among caregivers of individuals with schizophrenia or schizoaffective disorder is significantly higher than the national norm, according to the study. It also concluded

that distress felt by people caring for loved ones with severe psychiatric illnesses was higher than that felt after a major natural disaster, Hurricane Sandy.

The vast majority of caregivers surveyed were women, and 60% of those were parents to a child with schizophrenia or schizoaffective disorder. Only 40% of those lived in the same household as their loved ones.

In the majority of findings, the distress was found to be caused by the increased demands on the caregiver and the amount of time and effort that person needed to devote to providing care. The second highest distress factor stemmed from the fear that a loved one would stop taking their medication and relapse into psychosis.

The authors argue that programs designed to provide

*Continue on Page 2*

## Inside this Issue

Feature Story .....	1 & 2
Love: Learning to Understand.....	2
Reset the Bar .....	3
Calendar of Events .....	4
Membership Form .....	4

*Continue from Page 1*

support to caregivers could prevent elevated distress levels, both for the caregivers of individuals with serious mental illness and the general population. In particular, the research showed that additional social support would reduce caregiver distress by almost 20%, bringing their level of distress close to the average amount felt in the United States. Meanwhile, reducing the financial burden felt by caregivers was shown to reduce distress by more than 10%, while increasing their emotional rewards would lower the psychological distress by 9%.

More than 8.4 million Americans were caregivers to an individual with mental health related issues, according to 2015 estimates. Four in 10 of these individuals found it difficult to manage their own health due to the extreme stress of caring for their loved one.

Greater attention and compassion to the dedicated people caring for their loved ones with serious mental illness is needed. The significant psychological distress felt by caregivers should be met with initiatives to bolster their support network and reduce their anxiety as they embark on the challenging tasks of caring for someone with serious mental illness.

#### **References**

Lerner, D. et al. (February 2018). [Psychosocial distress among caregivers of individuals with a diagnosis of schizophrenia or schizoaffective disorder](#). *Psychiatric Services*.

## **Personal Perspective**

### **Love: Learning to Understand**

*By M. Coleman*

I'm a college student who went from speaking at school events, going to class, and hanging out with my friends to speaking to voices in my own head, going on wild spending sprees complete with reckless sexual behaviors, and hanging out with thoughts of self-harm and suicidal ideations. I went from thinking I could beat Jesus's disciples in a game of bowling to wandering around in the middle of the night because "she" was after me. Being diagnosed with Bipolar Disorder at the age of 21 was difficult, but the real harm came when my support system disappeared in response to my abnormal behavior.

Love is not getting frustrated with someone for struggling then giving up on them because you don't know what to do or because you don't understand. Instead, love means being able to admit that you do not understand, knowing that it is okay, and then doing everything you can in order to learn how to understand.

Sometimes we expect things to look a certain way or expect people to grow at a certain pace. Unfortunately, things are not always that simple and things don't always go according to our plans. Mental illness looks different in everyone and learning how to appropriately respond to those who suffer from a mental illness is key to their success and yours in supporting them.

Supporting a loved one who has a mental illness is not easy, in fact, it's a long process and you yourself will need support. There will be a lot of statements and questions running through your mind. Words like "Where did I go wrong?" "Why does this keep happening?" "What is the root?" and even "Will my loved one ever be the same again?" will begin to pop up.

It is natural to think these things and ask questions when we don't understand. When we do not understand something, we can begin to assign blame and try to diagnose people from our own understanding. The interesting thing is even psychiatrists and other medical professionals do not fully understand mental illness. Do not expect to understand everything right away, or ever.

My family and I have learned a lot since my diagnosis. We first had to accept the fact that I have a mental illness but it can be treated and it's not anyone's fault. Once you get past that, everything else will come a bit easier. We all have a responsibility to educate ourselves about mental illness and the effects it can have on an individual.

Your loved one does not need you to know all the answers; they just need you to be there for them. If you do not understand, ask your loved one what they are feeling, reach out for help, and log onto sites like NAMI.org to further understand types of mental illnesses. Remember, love means never giving up on someone and learning how to understand even when it's tough.

## Family-to-Family

### Reset The Bar

By: Mark Voegele

*Editor's Note: Mark Voegele is an engineer, former university Dean and Professor, and a NAMI Tri-Valley Family-to-Family instructor.*

Like it was yesterday... We had just come home from the electronics store with our first video camera. Our munchkin was right around 12 months old. We'd unpackaged our new memory catcher, put in the battery and were starting to experiment when it happened.

At this perfect moment our not-yet-a-toddler started toddling. He stood up not 3 feet from me and took his first steps. I quickly turned the camera on him as he started his show. He turned and took off for the dining room, stepped through the doorway into the kitchen, immediately turned left into the hall that would wrap around again and come right back at me in the hallway.

There he was discovering this new mode of locomotion and loving it. He waddled down the hall, arms out wide for balance, and giggling like only a baby can giggle. This whole perfect scene captured on tape. We were as tickled at the timing as we were about his development and almost as giddy as he was about his own achievement.

That son is now 33 years old. If that man started walking around the house with the same awkwardness today I'd think he was either goofing around or something terrible just happened to his motor functions. Why is that?

It is because he has progressed. He has better honed skills at motivating his body as a practiced biped. Through the years the bar by which I measure his achievements has moved. It is a natural progression for our expectations of others to change with time and observed progress.

When a family member is diagnosed with a brain disorder a litany of cognitive and

emotional responses overwhelm us—fear, anger, pain, hopelessness, confusion, grief. Be it an instant or a gradual awareness we, the family, all reach the point where we experience this profound sense of grief and loss as all our hopes, dreams, and expectations for that loved one dissolve away before our eyes. We fear we may never again feel the joy of their accomplishments.

Reset the bar. If you want to again know the joy of the developmental years, you need to reset the bar. If the loved one with a disorder is your spouse or sibling and you want to be as happy as you were when they got that degree, promotion, or new job, reset the bar.

In Family-to-Family we spend weeks teaching the students about the realities of brain disorders. We strive to liberate the attendees from crisis and grief and confusion through knowledge and understanding. Our goal is to move you, the caregiver, from sufferer to acceptor to advocate.

Reset the bar. This is where, in my experience, acceptance begins. Stop focusing on the loss. Observe the illness and its manifestations. Learn the new norm. Wear their moccasins. Look through their eyes. Empathize with their experience. Redefine what qualifies as an achievement.

Reset the bar, so you can gently promote genuine development and growth. It may be as basic as bathing voluntarily or as substantial as holding a part time job. Because you know what qualifies as an achievement, you can now advocate for them to reach new goals and find great joy and pride in their achieving them.

One final note. Everyone I know that has genuinely reset the bar for his or her loved one has a better-lived experience as a caregiver. They are happier more of the time. They manage crises better. They overcome challenges better. They are less stressed by the challenges in caregiving and in everyday life. I am not promising utopia. I am merely sharing what I have observed and experienced...Now. Go. Reset the bar.

## NAMI Tri-Valley Support Group Calendar

**Family/Caregiver Support Group - Livermore**  
Meets 2nd Monday of each month:

*Monday, March 12, 2018*

*Monday, April 9, 2018*

*Monday, May 14, 2018*

**7:00 p.m. - 8:30 p.m.**

Livermore Library Board Room  
1188 S. Livermore Ave., Livermore

Contact: Marsha McInnis 925.980.5331  
marsha@nami-trivalley.org

**Parent Resource & Support Group - Pleasanton**  
Meets 3rd Tuesday of each month:

*Monday, March 20, 2018*

*Monday, April 17, 2018*

*Monday, May 15, 2018*

**7:00 p.m. - 9:00 p.m.**

5674 Stoneridge Drive, Suite 114, Pleasanton

Contact: Marsha McInnis 925.980.5331  
marsha@nami-trivalley.org

**Family/Caregiver Support Group - Pleasanton**  
Meets 4th Monday of each month

*Monday, March 26, 2018*

*Monday, April 24, 2018*

*Monday, May 28, 2018*

7:15 p.m. - 9:00 p.m.

5674 Stoneridge Drive, Suite 114, Pleasanton

Contact: Marsha McInnis 925.980.5331  
marsha@nami-trivalley.org

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NAMI is a non-profit, grassroots, self-help, support and advocacy organization of consumers, families, and friends of people with severe mental illnesses, such as schizophrenia, schizoaffective disorder, bipolar disorder, major depressive disorder, obsessive-compulsive disorder, panic and other severe anxiety disorders, autism and pervasive developmental disorders, attention deficit/hyperactivity disorder, and other severe and persistent mental illnesses that affect the brain.

*Brainstorm is published by NAMI Tri-Valley, an affiliate of NAMI National and NAMI California.*



### Annual Membership Application

Name \_\_\_\_\_

Address \_\_\_\_\_  
\_\_\_\_\_

City \_\_\_\_\_

State \_\_\_\_\_ Zip \_\_\_\_\_

Phone \_\_\_\_\_

E-mail \_\_\_\_\_

NEW       RENEWAL

REGULAR (PER PERSON): \$40

HOUSEHOLD: \$60

OPEN DOOR: \$5

*The Open Door rate is available to those whose economic circumstances require it, and entitles you to the full rights and privileges of NAMI membership.*

### Donation

\$ \_\_\_\_\_ In Memory Of: \_\_\_\_\_  
\_\_\_\_\_

\$ \_\_\_\_\_ In Honor Of: \_\_\_\_\_  
\_\_\_\_\_

Membership dues are tax-deductible renewable 12 months from initial application. Membership entitles you to receive NAMI Tri-Valley Newsletter Brainstorm and NAMI National The Advocate. Tax I.D.# 72-1610675.

*Volunteer and make a major difference in the lives of those affected by mental illnesses.*

Please send this application form with your check payable to **NAMI Tri-Valley, P. O. Box 5563, Pleasanton, CA 94566**