



*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.*

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### Calendar:

- May 21st—Support Meeting in Carlisle
- May 24th—NAMI Connections
- May 31st—NAMI Connections
- June 4th—West Shore Support Mtg
- June 7th—NAMI Connections
- June 14th —NAMI Connections
- June 15th—NAMI Dauphin County Support Mtg
- June 18th—Support Mtg in Carlisle

### Contact Us:

P.O. Box 527  
 Carlisle, PA 17013  
<http://www.namipacp.org>  
[findhope@namipacp.org](mailto:findhope@namipacp.org)  
 Message line number:  
 240-8715

## May 18-24 is Older Adults Mental Health Week

*A message from the Mental Health Association of the Capital Region*

As America’s population ages, the need for mental and behavioral health services continues to increase. This week is dedicated to promoting mental health among the aging community and preventing discrimination against older adults who have mental health problems and other disabilities. To learn more, visit the American Psychological Association's [website](#).

**Did you know that older adults have the highest rates of suicide?** In 2013, the highest suicide rate (19.1) was among people 45 to 64 years old. The second highest rate (18.6) occurred in those 85 years and older. Younger groups have had consistently lower suicide rates than middle-aged and older adults. In 2013,

adolescents and young adults aged 15 to 24 had a suicide rate of 10.9.



In an effort to help older adults and their caregivers understand the healthy aging and mental health literacy, the Mental Health Association of the Capital Region (MHACR) offers a course titled "Healthy ABCs: Older Adult Health Literacy Program". The course was developed by the Pennsylvania Behavioral Health and Aging Coalition and funded in part by the Department of Health and Human Services, National Institutes of Health, National Library of Medicine, and the University of Pittsburgh. To book a training please contact MHACR at [717-236-3300](tel:717-236-3300) or [julia@mhacr.org](mailto:julia@mhacr.org).



### MAY MEETING

## NAMI PA of CUMBERLAND and PERRY COUNTIES

### THURSDAY, MAY 21, 2015 at S.T.A.R.

253 Penrose Place, Carlisle, Pa.

[See page 4 for directions]

7:00 —8:30 PM Support Meeting

**support**

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**Teresa Kerns**

**Joy Mullen**

**Kelli Murphy-Godfrey**

**Don Paleski**

**Sarah Roley**

**What: Support Group Meeting**

**When: Meets 3<sup>rd</sup> Thursday of each month**

**Location: STAR (253 Penrose Place Carlisle, PA 17013)**

**Time: 7:00 pm up to 9:00 pm** there will occasionally be an educational program. 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 21, 2015**

7:00 to 8:30 PM Support Meeting

**June 18, 2015**

7:00 up to 8:30 PM—Support Meeting

**July 16, 2015**

7:00 up to 8:30 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 Hazel at 737-8864 for information.

**June 4, 2015**

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 Baptist Church, 530 Big Springs Road, New Cumberland, PA. Contact Beverly Riggins at 717-979-0519 for more information.

**THIS GROUP SHALL NOT MEET THIS SUMMER  
[June, July, and August]**

**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.

**June 15, 2015**

6:30 to 8:00 PM—Support Meeting



**Bipartisan Bill Introduced to Reduce Criminalization!  
Act Now to Urge Your Senators, Representative to  
Join as Co-Sponsors**

The excessively high rate of people with serious mental illness, including Veterans, who are incarcerated in jails and prisons is one of the profound tragedies in 21<sup>st</sup> Century America. In local jails alone, it is estimated that 2 million individuals with serious mental illness are booked into jails each year. People with mental illness and co-occurring substance use disorders are similarly overrepresented in state and federal prisons. Most of these individuals are not violent criminals but rather in need of quality mental health treatment and supports.

Earlier this week, a bipartisan group of legislators introduced the *Comprehensive Justice and Mental Health Act of 2015* in the U.S. Senate and House of Representatives. These bills ([S. 993](#) in the Senate, [HR 1854](#) in the House) update and reauthorize the Mentally Ill Offender and Treatment Crime Reduction Act (MIOTCRA) passed in 2004. Senators Al Franken (D-Minn.) and John Cornyn (R-Texas) are the Senate lead co-sponsors and Representatives Doug Collins (R-Ga.) and Bobby Scott (D-Va) are the lead co-sponsors in the House. The two bills were assigned to the Senate and House Judiciary Committees.

The bill incorporates the “Sequential Intercept Model” as a foundation for services. This is a comprehensive approach to services that emphasizes interventions at whatever stage of the criminal justice process a person is, whether pre-arrest,

post-arrest, during incarceration, or upon discharge into the community. It requires all relevant systems (criminal justice, mental health, substance abuse, consumers and families and others) to work together to design and implement strategies to reduce incarceration and improve treatment and rehabilitation. The bill authorizes funding for a variety of relevant services, including:

- Law enforcement training and partnerships such as Crisis Intervention Team (CIT) programs;
- Specialty Courts such as Veterans Treatment Courts and Mental Health Courts;
- Treatment and services in correctional settings, including alternatives to solitary confinement;
- Programs to assist people transitioning out of corrections and reentering communities, including mental health and substance use treatment, housing and employment.

**Action Needed:**

Finding additional co-sponsors and supporters in the Senate and House will be critical to moving these bills forward. **So far no Representatives or Senators from Pennsylvania have co-sponsored either of these bills.** Please contact them and urge them to join as co-sponsors of this important legislation.

**Thank you for advocating for passage of these important bills!**

## WANT TO IMPROVE YOUR MENTAL HEALTH?

How can caring for something else improve your mental health, well-being and level of happiness? ([How To Be Happier?](#)) After all, when you are struggling with a mental illness, finding a joyful mindset is stressful, even painful at times. Who needs more work? Consider this, however, when you take responsibility for something or someone, you could gain some happiness without realizing it.

Even though you should always put your personal happiness first, there are ways to improve your mental health, happiness and well-being without it being work. When you focus on caring for something or someone else, you feel a sense of compassion and contentment. Alongside that contentment often comes a feeling of happiness because you are proud of the responsibility you have taken on. When you are proud of yourself, you are able to wash away some of the insecurities that have been clinging to you and replace them with feelings of confidence and positivity.

### 3 Ways To Improve Mental Health, Well-being and Get Results

1. **Taking Care of a Plant.** When you have a plant to take care of, you not only must water it and continue to check the health, you get to watch it grow and blossom. Just buy purchasing a small bamboo tree, cactus or even picking flowers, you can support the life of a plant while supporting your life as well.
2. **Taking Care of a Pet.** Whether you are taking a care of a goldfish or a dog, you are providing happiness for a living, breathing life and just by having that responsibility, you will be able to improve your focus. Fostering an animal or dog/cat-sitting can be a heart-warming way to show you care. ([Animal Therapy: Easing Anxiety With An Animal](#))
3. **Volunteering.** When you are doing something without payment, you are doing those activities out of the goodness of your heart. Volunteering is a great way to give back and, in turn, fill yourself with the compassion you shared with others.

*“Talk with someone who understands...  
Someone just like you.”*

*Too often, mental illness is an isolating experience, accompanied by profound anxiety. For people with any mental illness, talking with someone to share coping strategies and insights, as well as problems and concerns, can be an important link to the path to recovery. This group provides a place that offers Respect, Understanding, Encouragement and Hope. It offers a casual and relaxed approach to sharing the challenges and success of coping with mental illness*

**When:** Each Sunday from 6:30 PM to 8:00 PM

**Where:** S.T.A.R., 253 Penrose Place, Carlisle, PA 17013 (see directions on this page)

**Who:** For Individuals Living with Any Mental Illness

**Group Leaders:** Joy , NAMI Nationally trained Support Facilitator

**Contact:** Any group related questions can be directed to Joy at (803) 409-9702.

**WE’VE BEEN THERE: WE UNDERSTAND.**

NAMI Support Groups are free and confidential

No preregistration is required

Find us on the Web at:

WWW.NAMI.ORG/CONNECTION and

WWW.NAMIPACP.ORG

Find us on Facebook at:

WWW.FACEBOOK.Com/NAMIPACP

# JOIN US FOR 2015

**\$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 2015**

**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.



**NAMI 2015 NATIONAL CONVENTION**  
JULY 6-9 • SAN FRANCISCO  
Super Saver registration ends March 15.  
**REGISTER TODAY**

EMBRACING THE FUTURE

- Drive Advocacy
- Engage the Youth
- Build a Movement
- Leverage Technology
- Strengthen the Organization

# Every Story Has the Power to Save a Life

By [Eliza Williamson](#) | Apr. 28, 2015

On a chilly day in the fall of 1992, I walked into the education building at Moravian College for the first of what would be thousands of times. It was my first class, aptly named



Foundations in Education. The professor had already written two things on the blackboard in perfectly looped cursive:

1. My name is Dr. Sandra Fluck (pronounced like book).
2. We are all both teachers and learners.

I have never forgotten either, although the latter is really at the core of why I love being a NAMI teacher. NAMI embraces the idea of *group wisdom* in all facets. We believe that each participant brings with them a wealth of strengths and skills and experiences.

In NAMI classes there is not one qualified expert who shares their knowledge—there are many. In fact, the number of experts depends on the class roster: in our Leominster, Mass. [NAMI Peer-to-Peer](#) class we have 25 wise souls. In our class in Concord there are 15! Each week in class I witness group wisdom in action. It is exciting to see the support, validation and troubleshooting that flows organically between people with similar experiences. It is thrilling and energizing.

Twice a week this spring I have the opportunity to pay it forward in the hopes that my own knowledge will lessen the struggle for someone else. So on Thursday afternoon and Friday morning I have empathy and support and my ninja-like coping skills at the ready. Sometimes I share, but the tools I use most are my ears. There is so much good stuff to take in. I have never left a class without a tidbit that made me think or a new strategy I wish I had thought of or a moment that solidified for me why I do this work. Every week, each class nourishes me.

As a writer, I believe stories save lives. As a NAMI Peer-to-Peer teacher, I watch it happen. Stories connect us; they tether us; they offer hope; they make us laugh. Stories give us perspective and give words to the unsaid and remind us we are not alone.

In [all NAMI classes](#), personal experience is revered. We know that the very act of telling your story is hopeful. By putting pain and suffering in context we see that it is one piece of your life, not the entirety. Whenever people share their stories in class, a palpable shift takes place. When a person gives voice to the dark parts of life—the places where shame and fear and loneliness fester—it gets lighter.

The storyteller shares and the group listens and it is healing. A burden is lifted from the teller. Things aren't as heavy when you have help holding them.

It is a process that is as simple as it is profound: I am here, maybe I am OK, but I am not alone. Those moments, really are magic; it's a little piece of magic called NAMI.

See more at: <http://www.nami.org/Blogs/NAMI-Blog/April-2015/Every-Story-Has-the-Power-to-Save-a-Life#sthash.yO1tSo84.dpuf>

## [Teens & Young Adults](https://www.nami.org/Find-Support/Teens-and-Young-Adults) from <https://www.nami.org/Find-Support/Teens-and-Young-Adults>

Mental health conditions are common among teens and young adults. 1 in 5 live with a mental health condition—half develop the condition by age 14 and three quarters by age 24.

For some, experiencing the first signs can be scary and confusing. Discussing what you are going through with others is an important first step to getting help. Speaking up and asking for help is a sign of strength. You will be amazed by the support you get simply by asking.

A mental health condition isn't your fault or your family's fault—it develops for complicated reasons that researchers are only starting to understand. But we understand a lot about how you can live well with a mental health condition—and you have the power to take the steps necessary to improve your mental health.

Mental health services and supports are available and the earlier you access them the better. Many teens and young adults live full lives with a mental health condition. More and more teens and young adults are speaking out about their experiences and connecting with others. Check out [Ok2Talk](#) to see what others are saying. You are not alone—there are others out there going through the same things you are.

### [About OK2Talk](#)

Teens and young adults who live with mental illness can feel hopeless and alone. Many don't know what's wrong with them but feel like it's their fault. Those who understand what is happening fear they can't be helped. Because of the stigma attached to mental illness, it's often hard for those suffering and their families and friends to talk about what they're going through. But help is available, and it works.

The goal of OK2TALK is to create a community for teens and young adults struggling with mental health problems and encourage them to talk about what they're experiencing by sharing their personal stories of recovery, tragedy, struggle or hope. Anyone can add their voice by sharing creative content such as poetry, inspirational quotes, photos, videos, song lyrics and messages of support in a safe, moderated space. We hope this is the first step towards getting help and feeling better.

## The ABLE Act - A New Tool for Special Needs Planning

*This installment of the Voice was written by Robert B. Fleming. Robert is a partner in Fleming & Curti, PLC, a Tucson law firm focusing on special needs planning, trust administration, guardianship/conservatorship and estate planning. He is a Fellow of the American College of Trust and Estate Counsel, and also of the National Academy of Elder Law Attorneys. He has been a member of the Special Needs Alliance since its founding, and was one of the original co-authors of the SNA's [Handbook for Trustees](#), the free online guide to managing special needs trusts.*

If you want to set aside money for the education of a child (or a grandchild, or anyone else), you can choose from a variety of options. One popular choice is to establish a "529 Plan" fund. These education accounts are named after the tax code section authorizing their use, and they make it easy and inexpensive to create education accounts.

Advocates have long championed a similar concept for people with disabilities. Years of legislative work finally resulted in approval of the Achieving a Better Life Experience (ABLE) Act last December. The new law allows states to set up programs that permit people with disabilities - or their family members - to make contributions to similar accounts. Rather than focusing on educational needs, the new ABLE Act accounts are to help pay for disability-related expenses - and there are a few other differences between ABLE Act and 529 Plan accounts. The new law creates interesting planning possibilities.

Though many people with disabilities will benefit from the ABLE Act, not everyone will. There are a number of limitations on the use of the new accounts, including:

- Only individuals whose disability was established before age 26 can set up ABLE Act accounts. This may seem unfair to people who acquired their disabilities later in life (or who might have been disabled but undiagnosed at earlier ages), but the age requirement was designed to limit the number of people who could qualify.
- Only individuals living in a state that has authorized ABLE Act accounts can participate. If a given state declines to authorize ABLE Act accounts at all, its residents cannot create ABLE Act accounts.
- Only one ABLE Act account can be established per individual but there is no limitation on the number of individuals who can contribute to that one account.
- Total contributions for the benefit of a given ABLE Act beneficiary cannot exceed \$14,000 in a single year. That figure is expected to increase by \$1,000 every few years, but will always

be keyed to the maximum federal gift tax exclusion amount.

- Upon the death of an ABLE Act participant, every dollar remaining in the account - including gifts from family members, and earnings in the account itself - must be paid to the state Medicaid agency to repay costs of care received by the participant during life. If the account should grow large enough to fully repay that Medicaid cost, any remaining funds can go to family members or other beneficiaries.
- If the ABLE Act account exceeds \$100,000, the participant will lose eligibility for Supplemental Security Income (SSI) - but not for Medicaid. The account can grow to a much higher number (between \$235,000 and \$452,210, depending on the state) before Medicaid eligibility is lost.
- While ABLE Act funds can be used to pay for "qualified disability expenses" (a term that is not yet fully defined), any payments for other purposes may mean the account is instantly countable as a resource, disqualifying the participant from SSI and Medicaid eligibility.

Those are the most important limitations, but they will not be a problem for many ABLE Act participants. Individuals with disabilities (and their family members) might well wonder whether the ABLE Act offers a useful alternative for them. Who will most likely benefit from ABLE Act accounts?

### **The beneficiary who saves money.**

Supplemental Security Income payments are limited to \$733/month (in 2015). Some people who qualify for SSI receive a state supplement to that figure, and a few might qualify for additional benefits that increase that figure slightly. It can be very hard to save money on an income that is so limited.

Some individuals with disabilities do manage to save money, though. For the beneficiary who is regularly trying to figure out how to spend down below the \$2,000 asset limitation level, the ABLE Act might have opened up a very attractive opportunity. Is your personal account getting close to \$2,000? You might be able to move, say, \$1,000 into your ABLE Act account, and not have to buy a new computer, or furniture, or a prepaid burial account. Depending on your finances and the final government regulations, you might actually be able to save money for the later purchase of a vehicle, or possibly even a home.

### **The beneficiary with a small inheritance or personal injury lawsuit.**

If you are an SSI or Medicaid recipient, and your grandmother leaves you \$10,000 in her will, you will lose your SSI (and might, depending on your state, lose Medicaid eligibility as well). Same if you are slightly injured in a car collision and your net settlement is \$12,000.

*(Continued on page 7)*

#### ASSISTED OUTPATIENT TREATMENT DEEMED AN EVIDENCED-BASED PRACTICE BY FEDERAL AGENCY

Acknowledging a substantial body of research, the federal agency that oversees mental health services and substance abuse treatment has recognized court-ordered outpatient treatment as an evidence-based intervention for people with severe mental illness who struggle with voluntary treatment adherence.

The Substance Abuse and Mental Health Services Administration (SAMHSA) last week added the practice commonly known as [assisted outpatient treatment \(AOT\)](#) to the National Registry of Evidence-Based Programs and Practices (NREPP).

"The federal agency charged with coordinating programs for adults with mental illness reviewed the evidence and found that AOT is an evidence-based intervention for reducing the dire consequences of nontreatment like repeat hospitalization, violence and suicide," said Doris A. Fuller, executive director.

"Policymakers have another clear signal that passing and implementing AOT is a reasonable means of improving outcomes for people with severe mental illness," the executive said.

AOT provides court-ordered treatment in the community to people with serious mental illness and a history of treatment non-adherence and commits service providers to delivering appropriate care to the most high-risk, high-need individuals. The federal agency added [outpatient commitment to NREPP](#) after an independent assessment concluded the program met its requirements for demonstrating positive outcomes in multiple, rigorous peer-reviewed studies.

The value of the intervention for qualifying individuals is also recognized by the American Psychiatric Association, the National Sheriffs' Association and the International Association of Chiefs of Police.

SAMHSA's designation follows recognition of AOT by the US Department of Justice, whose Office of Justice Programs deemed it to be an effective and evidence-based practice for reducing crime and violence in 2012. Forty-five states and the District of Columbia currently authorize the use of some form of court-ordered outpatient treatment for individuals with the most severe psychiatric diseases.

"This impartial assessment adds further weight to the voices of advocates across the country seeking to implement AOT laws to save lives," said Fuller. "Far too many communities face tragic outcomes because of a failure to effectively use this common-sense solution to serve those who are most severely mentally ill."

The National Registry of Evidence-based Programs and Practices is a publicly available online database of mental health and substance abuse interventions. To be recognized as evidence-based, interventions must meet NREPP's requirements for review and be independently assessed and rated for quality of research and readiness for dissemination, according to the agency's website.

*(Continued from page 6)*

The ABLE Act opens up a new possibility. You might be able to move your small inheritance or personal injury settlement into a new ABLE Act account, and continue your benefits uninterrupted. That way you can figure out how to spend the money over the next few months or years, rather than having to get it spent down within the next two or three weeks.

Note, though, that this only works for amounts under the \$14,000 annual exclusion amount - at least in most cases. If the money arrives in, say, December, it might be possible to spread contributions across two calendar years. There might be other opportunities to spread payments out to fully utilize the ABLE Act. It will be very difficult, however, to handle a \$50,000 inheritance or a \$100,000 personal injury settlement this way.

#### **The parent (or grandparent) with a small estate and a fear of lawyers.**

Do you intend to leave money to your child (or grandchild, or family friend) with a disability? You almost certainly should be setting up a special needs trust. But if you really are only going to leave, say, \$10,000 to your child, then you could consider making the gift to an ABLE Act account. You will subject your money to the payback requirement upon your child's death, but maybe that is not a very large concern for you.

#### **The family very interested in giving their child more autonomy and control.**

Maybe you are less worried about the amount of money and the possibility of having to pay back the state Medicaid agency, and more concerned about the personal dignity and autonomy flowing from your child having control over at least small amounts of money. You can't put \$5,000 into their checking account because it would make them ineligible for SSI (and maybe for Medicaid). But you could put that same \$5,000 into an ABLE Act account and your child could have almost full control over the use of the funds. The value of that self-determination might well be worth more than the limitations in the ABLE Act.

#### **The special needs trustee who wants to give a beneficiary more control.**

As with family contributions, it might sometimes be a good idea for a special needs trust to put money into an ABLE Act account. It's not yet completely clear when this might work - but small payments from at least some kinds of special needs trusts might benefit the ABLE Act participant.

There are quite a few unanswered questions. The Internal Revenue Service and the Social Security Administration both need to adopt regulations defining terms and setting final limits. States need to adopt ABLE Act account legislation (though a handful are well on their way to accomplishing that step already). The financial industry needs to actually set up the accounts. Then, and only then, will you be able to open an ABLE Act account.

Will ABLE Act accounts be a huge game-changer for people with disabilities? No - but they are one more tool available to individuals and their families. You should discuss ABLE Act accounts with the lawyer who helped you prepare your special needs trust. Thank Congress for introducing this new option and all of the advocacy organizations who spent years lobbying Congress to pass the ABLE Act. Finally, advocate in your state for the enabling legislation necessary before you can use the ABLE Act.

**About this Newsletter:** We hope you find this newsletter useful and informative, but it is not the same as legal counsel. A free newsletter is ultimately worth everything it costs you; you rely on it at your own risk. Good legal advice includes a review of all of the facts of your situation, including many that may at first blush seem to you not to matter. The plan it generates is sensitive to your goals and wishes while taking into account a whole panoply of laws, rules and practices, many not published. That is what The Special Needs Alliance is all about. Contact information for a member in your state may be obtained by calling toll-free (877) 572-8472, or by visiting [the Special Needs Alliance online](#).

: "Reprinted with permission of the Special Needs Alliance - [www.specialneedsalliance.org](http://www.specialneedsalliance.org)."

# The Role of Caregivers for People with Mental Illness

Written by HealthyPlace.com Staff Writer

*Important information about the role of caregiver for someone with a mental illness.*

Has a friend/relative been diagnosed with a mental illness? Do you find yourself caring for your friend or relative? Are you unsure how best to help? Do you know where to get help for yourself or for your friend or relative? Are you looking after yourself? The following tips give some suggestions and guidelines that will help you and assist you to be a better support to your friend or relative facing a mental illness.

## **How do you feel?**

Caring for someone with a mental illness is a complex and demanding role, and it is normal for carers to experience a range of feelings about it. Initially, you may experience disbelief ("This can't be happening"). Later, you may develop seemingly conflicting feelings of anger, shame and love. It's important to know this is normal, and that no feelings are right or wrong. Typical emotions include:

**Guilt** - You may feel responsible for the illness but no one is to blame. You may feel guilty about not wanting to be a carer, or perhaps think, "I'm not doing enough."

**Shame** - The stigma around mental illness can cause embarrassment. You may worry about what others think.

**Fear** - It is normal to fear for the person's future or to worry about what will happen to him or her if you can't cope.

**Anger/frustration** - You may feel frustrated with being a carer, or angry that others don't pitch in. You may think, "My friend/relative doesn't appreciate what I do or what I have sacrificed for them."

**Sadness** - You may grieve for the loss of the relationship as it was, and the life you once knew. You may feel sad about the loss of opportunities and plans for both yourself and your friend/relative.

**Love** - Your love for your friend/relative may deepen and you may feel very motivated to help.

Your feelings and motivation may change over time. In the early stages of caring for someone people often focus on gathering information and finding their way through the mental health system. As acceptance and understanding grow, many long-term carers find that their attention turns to a more political focus such as lobbying and advocacy.

## **How do I understand what is happening?**

Mental illness is a broad term used to describe many conditions including mood and anxiety disorders, personality disorders and psychotic disorders such as schizophrenia. These illnesses can affect every part of a person's life including work, relationships and leisure.

There are many myths about mental illness. What you have heard may not be true so it is best to find out the facts. Remember that people with mental illness are not defined by their illness. They still have likes, dislikes, opinions, talents and skills. They are mothers, brothers, friends, colleagues etc. Their rights and individuality need to be respected.

## **a) Understanding the illness**

A mental illness, like a physical illness, is treatable. Learning about the mental illness may ease fears about the unknown or unfamiliar. It is important to find out about:

### • **The features of the illness**

Gather information from family doctors, psychiatrists, mental health organizations and internet sites. Keep a diary of any problems or symptoms you need to ask about. Find out the warning signs of relapse.

### • **Treatment options**

These may include medication, cognitive behavioural therapy, counselling, group programs, self-help approaches, stress management etc. With each of these, make sure you understand what is being offered and how it will help. Think about combining treatments. Keep a diary and write down questions as you think of them and add the answers when you have them.

### • **Medications and their side effects**

A doctor or pharmacist will be able to help. You need to know the medicine's name; what it is used for; how long it needs to be taken for; what happens if a dose is missed; what to do if side effects arise; how it could interfere with other medications including over-the-counter, supermarket and herbal medications; how it could affect any other illnesses the person may have; what should be avoided while taking the medication; and the cheapest brand.

## **b) Understanding the mental health system**

- The first step is to see a family doctor, psychologist or psychiatrist. To see a psychiatrist, many insurance companies require you to get a referral from a GP.
- Find out the structure of your local (county) mental health service. Keep handy a list of important phone numbers including the number of the crisis/assessment team, doctor/psychiatrist, hospital, support groups etc.
- Investigate other treatment services including private psychiatrists, psychologists and your community/county health center.

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- Look into local professional and community support services for carers and people with mental illnesses. Many communities have local chapters of NAMI (National Alliance for Mentally Ill) and DBSA (Depression Bipolar Support Alliance).

#### **Communication:**

"Everything I say and do is wrong" Good communication is difficult at the best of times. When situations become really difficult, it is even more important to share feelings and thoughts in a way that avoids unwelcome responses.

#### **a) Non-verbal communication**

Communication is more than what we say. We also communicate in ways that are non-verbal. You may have heard the phrase, "Actions speak louder than words". That means non-verbal communication can be more powerful than words. It is thought that up to 70% of communication is non-verbal.

- **Posture and gestures**

Maintain an open posture, which means not crossing your arms which can be taken as unwillingness to listen. Try to avoid exaggerated movements such as pointing, waving your arms or putting your hands on your hips, which may appear aggressive or confrontational.

- **Facial expressions and eye contact**

Faces express feelings but sometimes when we speak, our facial expressions don't match the meaning of what we are saying. It is important to be honest and learn to share in a non-confrontational way what you are feeling and thinking. Maintain a comfortable level of eye contact: looking someone in the eye shows you are listening to them and not bored or frightened, although staring can cause the person to become uncomfortable or feel threatened.

- **Personal space**

We all feel the need to keep some personal space between another and ourselves. Standing too close can cause the other person to feel uncomfortable. If a person is feeling vulnerable or disturbed, standing too close can increase discomfort.

- **Voice tone and pitch**

Try to maintain your normal tone and pitch when speaking. Some situations may cause a carer to unnecessarily raise or lower their voice. Despite your best intentions, this can be disturbing.

#### **b) Discovering new ways of communicating**

Learning new ways of communicating with the person you care for can reduce misunderstandings. Pay attention to the words you use. Be specific and concrete: however avoid oversimplifying, as it can seem patronising.

Carers may be accused of not understanding or listening. It is natural to defend yourself although arguments are not helpful. The symptoms of some mental illnesses can make communication difficult.

It is useful to think about how you communicate. The three aspects of communication listed below may provide some pointers and the techniques described can be used very effectively.

- **Listening skills -**

Listening to what a person is saying without interrupting can be difficult, especially when you disagree with what is said, but if you do this, you are more likely to be heard too. Acknowledgement is another aspect of listening. Acknowledgement is done by making sounds like "uh huh" or "Mmmm". This does not mean that you agree but shows you are paying attention. Encouraging your friend or relative to fully explain what they are thinking and feeling helps you understand what he or she is going through. Use phrases such as: "Tell me more", "What happened then?", "When did the problem start?"

- **Reflecting meaning -**

You can show you understand someone by reflecting his or her feelings and the reasons for them. It is important to reflect the correct intensity of feeling. If a person is terrified, say, "You're really terrified", not "So you feel a little bit scared". You might say, "You're feeling really terrified because the voices are saying that people are spreading lies about you". Reflecting meaning is also a good way to clarify exactly what the person is saying.

- **Sharing your feelings in a non-confrontational way -**

Carers often feel that everything revolves around the person with the illness. But carers have a right to express their feelings too. To share your feelings in a non-confrontational way use 'I' statements ("I feel upset and worried when you...") rather than 'You' statements ("You make me so angry when you..."). 'I' statements show you are taking responsibility for your feelings, not blaming others.

**These responses may help.**

***"I didn't realize that what I said affected you that way. Now that I know, how about we sit down and talk about it calmly."***

***"Tell me how you would like me to respond."***

Remember that when you feel angry or stressed it is easy to explode with sweeping, broad generalizations and criticisms, but these only block effective communication. Learning any new skill can take time, so don't be too hard

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on yourself. It may take time for others to adjust to a new way of communicating, but keep trying.

Learning any new skill can take time, so don't be too hard on yourself. It may take time for others to adjust to a new way of communicating, but keep trying.

### Looking at problem behaviors

A person with a mental illness is still responsible for his or her actions. You might need to agree on what is and is not acceptable behavior, for example, you may agree that your child/relative can smoke cigarettes in the home, but not use illegal drugs. It may help to discuss with a mental health professional what possible behaviors to expect and which need to be accepted as part of the illness. Some behavior can be harmful or distressing either to the person, your relationship, or others. For example

- If your child is playing loud music in the middle of the night
- If your friend is demanding so much of your time and attention that you don't see your family
- If your partner empties the bank account on a spending spree

You may need to decide how to approach these issues. Be aware of your own personal boundaries and discuss the situation with your friend or relative. Work together on a solution. If the agreed solution is not working, talk to a doctor, case manager, or counselor about what you can do.

### Empowering the person

It is important to relate to your friend or relative as an individual, not just in terms of his or her illness. He or she has the right to make decisions, including decisions about treatments. Imagine how you would feel if decisions were always made for you and not by you. Remember what the person was like before the onset of mental illness - he or she is more than likely still that person. Recognize the difficulty of your friend's/relative's situation. Acknowledging the person's strength and ability to face such situations can help minimise his or her sense of powerlessness.

### "...But I don't have time for myself..."

When caring for a friend or relative, the carer's needs often get lost. In order to care for another, you also need to take care of yourself.

### Self-care checklist

- Do I have someone I trust to talk to about my experience?
- Do I get enough breaks from caring?
- Have I got regular times for relaxation?
- Am I getting regular exercise?
- Am I eating regular nutritious meals?
- Do I get enough sleep?

### How to take care of yourself

- **Taking breaks -**  
Recognize your limits - no one can be a carer every minute of every day. Make sure you go out and continue doing activities you enjoy. Is there a relative or friend who would be willing to share the role of carer? For a longer break,

consider arranging respite care.

- **Health -**  
Maintaining good health is the best way to withstand stress.  
**Regular exercise** - Exercise can be as simple as walking, gardening, dancing, yoga, or anything that gives you a gentle workout.  
**Relaxation** - Listening to pleasant music, meditating or reading an enjoyable book are a few ways of relaxing.  
**Diet** - Regular well-balanced meals will help maintain your energy levels and keep you physically and mentally well.
- **Support -**  
Having a friend or someone you can talk to about what you are experiencing, without judgement, is important. Sharing your experience can give you comfort, strength, and reduce feelings of isolation. Join a local support group through NAMI, DBSA or another organization.
- **Planning -**  
Planning ahead can make things more manageable. Include the person you care for in the planning process. You may need to plan: A day-to-day routine. It helps to have some structure in the day, such as regular meal times. Introduce gradual change to prevent boredom. A day-to-day routine. It helps to have some structure in the day, such as regular meal times. Introduce gradual change to prevent boredom.
- A plan of action in case of an emergency. Make a written agreement with the person you are caring for. Have a list of important phone numbers (GP, psychiatrist, case manager, hospital, crisis team etc) on hand.
- Have an up-to-date list of medications on hand, and find a friend or family member who is able to step in if you are suddenly unable to care.

### What if things are getting worse?

As a carer you are in a good position to notice changes in the person's condition. If his or her health or behaviour deteriorates, get help as soon as possible. Symptoms to watch for include hallucinations, withdrawal, severe mood swings, religious obsessions, delusions and excessive alcohol and drug use.

At times your friend or relative may feel suicidal. Be aware of the warning signs of suicide which include talking about suicide, feeling hopeless and/or worthless, giving away personal belongings, risk taking, withdrawing, tying up affairs and saying goodbye, or suddenly feeling happy or at peace. Take suicide thoughts and behavior seriously: ask the person directly if he or she is suicidal. Explain that you want to help. Get help for yourself.

**Caring for someone with a mental illness may be difficult and frustrating but may also be rewarding. Don't get discouraged. Try these tips and don't forget to care for yourself. Use all the resources available to you.**

### Sources:

Lifeline Australia

**NAMI PA**

**CUMBERLAND and PERRY COUNTIES**

Enclosed is my membership or my tax deductible donation (check or money order)

Payable to NAMI PA C/P - mail to PO Box 527, Carlisle, Pa. 17013

Individual membership [\$35]  Family membership [\$35]  Open Door [3\$]  Professional membership [\$50]  
 New member or  Renewal

NAME: \_\_\_\_\_ Date \_\_\_\_\_

STREET: \_\_\_\_\_ email: \_\_\_\_\_

CITY: \_\_\_\_\_ STATE \_\_\_\_\_ ZIP \_\_\_\_\_



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