

Synapse

Volume 14, Issue 4

Autumn, 2011

Newsletter of the Spastic Paraplegia Foundation

LEARN TO WINDSURF DAY!

Austin, Texas – June 4, 2011



www.austinwindsurf.org

Letter from the Editor,

September 2011

Dear Friends,

Suicide and depression are topics that tend to be avoided, glossed over or entirely dismissed in discussions with friends and family.

From my own life experiences, however, I can guarantee that most of us know someone or know of someone who has suffered terribly because of these two life realities.



Families who experience long-term illness, disease and caregiving issues have the additional burden of being more susceptible to mental health concerns. Our society, though making great progress in the areas of physical accessibility and inclusion, still tends to flinch when our emotions and mental health come into play.

I hope this edition of *Synapse* provides useful and thought-provoking information about these two uncomfortable topics. I believe depression and suicide are two issues that are as relevant to our community as those concerning research developments, exercise options, fundraising and community events.

Beth Anne Shultz, Editor

Your questions and comments are welcome. Please contact me via e-mail at bads.spf@wildblue.net.

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Life is not easy for any of us. We must have perseverance and above all confidence in ourselves. We must believe that we are gifted for something and that this thing must be attained.

– Marie Curie

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The Spastic Paraplegia Foundation Inc. (SPF) is a national, not-for-profit, voluntary organization. It is the only organization in the Americas dedicated to Primary Lateral Sclerosis (PLS) and Hereditary Spastic Paraplegia (HSP).

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TBD Medical Updates

Published four times a year for the HSP/PLS community. Available online at www.sp-foundation.org

The SPF is a non-profit 501(c)3.

Tax ID # 04-3594491

Combined Federal Campaign CFC #12554

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Updates and New Frontiers

Combined Federal Campaign

The Combined Federal Campaign (or CFC) is a fundraising campaign the Federal Government offers its employees to participate in each year. Employees pick which non-profits they would like to help and how much money to give. The amount they donate comes out of their pay in pre-tax dollars. Each year Millions of dollars are raised through the CFC campaign, but unfortunately, the Spastic Paraplegia Foundation doesn't get much of the money raised.



We would like to get your help to increase donations so that a cure for HSP and PLS can be found. All it takes is for more Federal employees to choose the SPF as the benefactor of their pre-tax dollars. If you know anyone who works for the Federal Government, please ask them to choose the Spastic Paraplegia Foundation. The SPF number is 12554. Law Enforcement Agencies, the U.S. Postal Service and the Veteran's Administration Services are all examples of government agencies.

The best way to get a commitment from someone is to ask them personally. If that is too uncomfortable, send a letter or an e-mail. The CFC selection process only happens in the fall, so now is the time to ask.

Thanks for your help in this great endeavor. Please feel free to contact me with any questions or concerns.

Jim Sheorn
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Support SPF with One Step a Month

Consider making a monthly donation to help SPF move a step closer to a cure. Our One Step a Month Program is a win-win! Recurring gifts allow us to plan ahead with confidence, making sure we take the best steps towards finding the cures for HSP and PLS. Plus, recurring donations allow you to give in a convenient, safe and secure way. Go to <http://www.sp-foundation.org/donate.htm>

Events

Learn to Windsurf Day Austin Windsurf Club Austin, TX

June 4, 2011

Twenty participants enjoyed their "land lessons" and then getting out on the water to windsurf. Although there was little wind, the participants were still able to get a feel for this delightful sport and had a lot of fun. A big thank you goes out to the members of the Austin Windsurf Club. Their efforts to make this event happen are appreciated. The money raised during this event will help fund the SPF's research efforts to find a cure for both PLS and HSP.

Bellingham Connection Bellingham Bay, WA

June 20, 2011

Eight of us met at the home of Carin and Sal Gurliaccio overlooking the Bellingham Bay. The gathering was organized by Dave Irvine, the State Ambassador for Washington and Oregon. Dave is working on having small regional meetings to get us energized for a big one! Things got off to a great start right away. Dave demonstrated his new DashAway to the group and we got to meet Sherry's assistance dog. Between the eight of us, we had a variety of stories to tell concerning experiences we have had with our walkers, canes, and medical experiences. Dave and Angie drove up from the Seattle area, Sherry and Lucas came over on the ferry from Orcas Island, and I (Jean) came over the border from Vancouver. I know we all thought our travels were well worth the effort! Those attending: Carin and Sal Gurliaccio, Sherry Vinson, Dave and Angela Irvine, Jean Chambers and Dave & Wilen Toperosky.

New Hampshire & Massachusetts Connection

July 9, 2011

Submitted by Laurie LeBlanc

Ten of us enjoyed a nice lunch in the beautiful state of New Hampshire. We had such a good time that we are going to try to schedule a connection every other month in a central location. Kathi Geisler gave a great demo of her DashAway walker and Nick was able to share his experiences with the SPG4 study that is in progress. All of us enjoyed catching up with one another and we were glad we had decided to get together. We feel this type of thing is very important to our SPF community.

**Colorado Connection
Erie, CO**

July 10, 2011

Eleven of us gathered for lunch at the Vista Ridge Golf Club. We had a great time!

**Rosella Vigliotta Golf Outing
Manorville, NY**

July 14, 2011

An incredible \$20,000 was raised at the First Annual Rosella Vigliotta Golf Outing! Congratulations to everyone involved in this grand accomplishment! This golf outing is named for Meredith’s grandmother who passed away last year. We felt it would be a great honor to name the outing in memory of her. The outing was organized and run by Meredith’s cousin, Lauren Giglio. Lauren was helped by Meredith’s sisters - Jennifer Holborow, Rachel Smith, Cortney Pettit, and Lindsey Hunter. Meredith’s mother, Christine Vigliotta, her Aunt, Donna Finnigan and her cousin, Phil Vigliotta also gave their time and effort to this event.

Approximately 70 people came out to golf and about 150 people attended dinner that evening. The weather was gorgeous (mid 70’s and sunny). Meredith designed the tee shirts with the logo “Hope in One”. They were green with white lettering. The front had a nice little insignia that said “Rosella Vigliotta Golf Outing” with SPF lettering in the middle. The backs of the tee shirts had a golf ball with crossed golf tees and the “Hope in One” logo. The tee shirts were sold for \$10 each. We had tons of donations from local businesses and their items were raffled off as gift baskets. One set of golf clubs, bag included, was raffled off separately and a 50/50 drawing netted \$630. Paul Leary, winner of the 50/50 drawing very graciously donated the funds back to the SPF.

The event was such a huge success that we have already booked the course for next year. The outing will be held on Thursday August 2nd, 2012 at the Rock Hill Golf and Country Club in Manorville, NY. Please visit www.rockhillgolf.com for more information. Again, thanks to everyone who made this first effort an astounding and memorable success!

**Southern California Connection Lunch
Rancho Palos Verdes, CA Aug. 20, 2011**

Fifteen people, some with PLS and some with HSP, and their caregivers, met for five hours today at the home of Malin & Lenore Dollinger. We had a splendid and far-reaching discussion of such topics as insurance, medications, exercise, speech problems, and role of caregivers, handicap aids, Medicare coverage,

service dogs, and transitions from canes to scooters to wheelchairs. Malin’s physical therapist, Sharon Walder, DPT, prepared a handout showing useful and important exercises that we can do at home. Malin showed everyone some handicap devices that facilitate dressing and daily living, including the 85 grab bars installed in his home. Though the meeting was held in a suburb of Los Angeles, some attendees came as far as San Diego and San Clemente. We renewed old friendships and made new ones and realized, once again, that “we are not alone.” Our next meeting will likely be in Orange County to facilitate attendance by those south of Los Angeles.



Those attending were: Maryla Fitch, Michelle Dennecker, Hoyt Johnstone, Sean Hogan, Paul and Bernice Rodriguez, Willis and Marilyn Bishop, David and Robin McNeil, Brenda Tabor, John and Jane Mitchell and Malin and Lenore Dollinger. Photo by John Mitchell.

**Texas Patient Connection Luncheon
Austin, TX**

Aug. 27, 2011

The theme of our 10th annual get-together was “I CAN.” We ate lunch at the Brick Oven Party Room and conversation was opened with talking about “I CAN” moments in dealing with HSP or PLS. Laughter mingled throughout the telling of our stories – whether we were relaying our need to tell people about our diagnosis or using canes and walkers in front of people for the first time. Everyone joined in and the luncheon was enjoyed by all.

**Mobility Matters Get Moving Forum
Connecticut**

Aug. 2011

Submitted by Kathi Geisler

The Mobility Matters Get Moving Forum in Connecticut was wonderful! There was lots of information to exchange and numerous mobility products to try out. This forum was so successful that another was held in Dover, New Hampshire on Sunday September 11th. If interested in attending such a meeting, please contact Kathi Geisler at kathisemail@aol.com or contact her at (978) 204-7432.

TeamWalks

Pennsylvania TeamWalk Magee Rehab Hospital Sept. 10, 2011

Submitted by Helen Kienlen

The first Pennsylvania SPF TeamWalk took place on Saturday, September 10th, 2011 at 10 a.m. It was a beautiful day. We met in the parking lot of Magee Rehab Hospital in Center City, Philadelphia, PA. The group enjoyed meeting one another and sharing life experiences. At 11:00 the group held a raffle for prizes, including a signed baseball from The Phillies. The TeamWalk raised about \$900.00 and made more people aware of HSP and PLS.

Atlanta Connection Atlanta, GA Sept. 11, 2011

We had delicious food, lots of fun, and many questions. Mike Difrakhsh, physical therapist, was our guest speaker. He was fantastic and answered all of our questions.

The Magnificent Mile Race 300 Hillsborough Street Raleigh, NC Sept. 18, 2011

Sarah Witt: srwitt@yahoo.com or www.magmilerace.com

The 6th annual Magnificent Mile will be held on Sunday afternoon. If you are traveling to Raleigh for the event, discounted rooms (\$79/night) are available for Friday and Saturday nights at the Clarion Hotel. Call 919-832-0501 and ask for a room in the Magnificent Mile block. Top-notch door prizes are part of the fun at this year's race. Leading the list are two laptop computers courtesy of Lenovo. We'll also be giving away ticket packages from the Carolina Hurricanes, the Carolina Mudcats, the Durham Bulls and NC State's Wolf pack football team. In addition, four lucky winners will receive a gift certificate for a one-hour massage from *A Touch Above Massage Therapy*. You must be pre-registered to be eligible for prizes.

Dallas Fort-Worth Connection Grapevine, TX Sept. 24, 2011

Jeff Smith: jss1162@sbcglobal.net or 817-926-6174
John Staehle: jstaehle@swbell.net or 817-496-3137

We are pleased to announce the first DFW PLS Connection will be held on Saturday, September 24, 2011 from Noon to 3:00 pm in the private dining room at Flips Patio Grill, 415 West State Highway 114, Grapevine, Texas (817-251-9800). You are invited to be part of this exciting first time event. Spouses, partners, family members and caregivers are all welcome (and encouraged) to attend. Discussion topics will include, but are not limited to, our individual PLS journeys,

conducting a PLS survey, websites dedicated to PLS, your experience with area physicians, and living with PLS from a caregiver's perspective. Cost is \$20.00 per person and includes lunch. To reserve a place at our table, please contact Jeff Smith or John Staehle at the numbers and/or addresses listed above. To confirm your reservation, please send your check, made out to the Spastic Paraplegia Foundation to: John Staehle, 3519 Ashley Street, Arlington, TX 76016-2774. Checks must be received no later than Thursday, September 22, 2011 unless prior arrangements have been made with John. Hope to see you there!

California TeamWalk Cures & Connection Weekend Pleasanton, CA Sept. 30 - Oct. 1, 2011

Linda Gentner: lkgentner@aol.com or 510-651-5676

A PLS & HSP Welcoming Dinner will be held Friday night, September 30 at the Hilton (pay for your own dinner). There will be a "Share & Compare" discussion time with dessert and beverage served after dinner. This is a time "just for us" and we have 21 people signed up so far. Get an early start on the weekend and stay at the hotel Friday night with no need to get up early on Saturday morning. This is when and where the real socializing begins! The TeamWalk or Roll, lunch and raffle will be held at the Valley Community Church on Saturday, October 1, 2011 (4455 Del Valle Parkway, Pleasanton). After the lunch on Saturday, Dr. Cathy Lomen-Hoerth, ALS Center at UCSF will be available for questions and share how the recent ALS news will benefit us. Please register ASAP. We currently have 60 people signed up with an almost equal number of attendees with HSP and PLS. We will be welcoming new "members" so let's make them feel right at home. The address for the hotel is: Hilton Pleasanton at The Club - 7050 Johnson Drive, Pleasanton, CA 1-925-463-8000. If you need an accessible room, please call Hem Raju at 1-925-737-5602 and make your reservations by September 16 to get the SPF room rate of \$69.00. Feel free to contact Lkgentner@aol.com for more information. The registration form can be found on the SPF website at www.sp-foundation.org/events.

Autumn in Carolina Rural Hall, NC Oct. 8, 2011

Don Wilson: don-wilson@earthlink.net

Autumn in Carolina will be held once more in Rural, North Carolina. We will utilize the same motel as in 2010. The Holiday Inn Select (Madison Park, Winston-Salem) has reserved a block of 10 rooms including 5 accessible (one with roll-in shower), all under the name of Autumn in Carolina. The rate for the rooms will be \$90.00 plus tax per night - no increase from 2010. The toll free number is 1-800-553-9595 and be sure to ask for rooms in the Autumn in Carolina block. The motel will hold these rooms until midnight on September

Mobility Marvels

RIGHT-SIDE HAND CONTROLS

by John Staehle

In the spring of 2005, it became evident I needed hand controls on my vehicle to continue driving safely. So I began an Internet search for the various types of available controls. Most controls are mounted on the left side of the steering column for left-hand operation. Though I'm right-handed, I've always preferred to steer with my left-hand – makes it easier to rest my left arm on the window opening on nice days and still touch the steering wheel. So my search rapidly narrowed to a few brands of push-pull systems.

The hand control system I purchased is floor-mounted on my right side. It looks remarkably like a floor-mounted gear shift lever. It was manufactured by Menox, a Finnish company that is now owned by AutoAdapt AB of Sweden. The system, including installation by an authorized dealer, was not cheap, but most quality systems aren't. The Menox website, www.menox.org/en/hand_controls, is still active and maintained by AutoAdapt. The standard unit, the one I have, comes with a rocker-switch-operated brake lock built into the handle grip which I can actuate with my index finger. It really comes in handy when you're waiting for a long traffic signal to change or are at a drive-up window. You can get lots of optional finger or thumb controlled actuator switches in the handle grip at additional cost - accelerator lock (if you don't have cruise control), horn, headlights, turn signals, windshield wipers, and the windshield washer.

As with all hand control systems, it takes practice, practice and more practice to get to the point where you can accelerate and brake smoothly with confidence. With the Menox system you must also learn to distinguish it from the actual shift lever. I learned that the first day I drove using the hand controls. Traffic was light and I was driving with the cruise control on. I came upon a traffic light that was changing from green to red. I calmly reached for the hand control lever and gently shifted the car into neutral. I quickly recovered and grabbed the correct lever, pushed it forward and came to a less than perfect stop.

I live in Texas and steering knobs (a.k.a. spinners) are illegal, but if you drive with hand controls, they are required. Mine is a low profile model, mounted on the steering wheel at 10 o'clock that allows me to "palm" the knob when turning the wheel, a more natural motion for me when driving with one hand on the wheel. I tried using a spherical knob, but found that I frequently over-steered turns and lane changes. Not good.

When I purchased my Toyota Rampvan, the dealer had no problems moving the controls from the SUV I previously drove. He just had to fabricate a riser to compensate for the van's lowered floor.

Floor-mounted hand controls on the driver's right side are not for everybody, but if that's your preference, the Menox system deserves a look.

Shows floor mount on riser to accommodate lowered floor of van. Driver seat has been moved back on transfer base for clarity



Shows how linkage attaches to brake and accelerator. Both pedals are accessible for foot operation when foot riser is installed

The Unspoken Worry

REAL MEN REAL DEPRESSION

An estimated six million men in the United States have a depressive disorder-major depression, dysthymia (chronic, less severe depression), or bipolar disorder (manic-depressive illness)-every year. Although these illnesses are highly treatable, many men do not recognize, acknowledge, or seek help for their depression.

While both men and women may develop the standard symptoms of depression, they often experience depression differently and may have different ways of coping. Men may be more willing to report fatigue, irritability, loss of interest in work or hobbies, and sleep disturbances rather than feelings of sadness, worthlessness, and excessive guilt, which are commonly associated with depression in women. Also, tragically, four times as many men as women die by suicide, even though women make more suicide attempts during their lives.

The truth is, depression is a real and treatable illness. It can strike at any age, from childhood into late life. With proper diagnosis and treatment, the vast majority of men with depression can be helped.

What makes depression different from the blues?

Depression is a serious medical condition that involves the body, mood, and thoughts. It affects how you eat and sleep. It alters your self-perception. It changes the way you think and feel. Men with a depressive illness can't just "snap out of it" or "pull themselves together," because depression isn't the same as a passing mood. Left untreated, depression may last for weeks, months, or years at a time.

Depressive illnesses can make routine tasks unbearably difficult. Pleasures that make life worth living-watching a football game, playing with children, even making love-can be drained of joy. Depression brings pain and disruption not only to the person who has it, but also to his family and others who care about him.

If you are experiencing some of the following symptoms, you may have a depressive illness. Ask yourself if you are feeling: sad or "empty"; irritable or angry; guilty or worthless; pessimistic or hopeless; tired or "slowed down"; restless or agitated; like no one cares about you; or like life is not worth living. You may also: sleep more or less than usual; eat more or less than usual; have persistent headaches, stomachaches or chronic pain; have trouble concentrating, remembering things or making decisions; lose interest in work or hobbies; or lose interest in sex.

If these symptoms are familiar, it's time to talk with your doctor. Depression is a real, medical illness that can be successfully treated, most often with medication,

psychotherapy ("talk" therapy), or a combination of both. Support from family and friends plays an important role as well.

It takes courage to ask for help

The feelings and behaviors that are part of depression can hinder a person's ability to seek help. In addition, men in particular may find it difficult to admit depressive symptoms and ask for help. It's important to remember, however, that depression is a real, treatable illness and is nothing to be ashamed about.

Thanks to years of research, a variety of effective treatments including medications and short-term psychotherapies are available for depressive disorders. Treatment choice will depend on the patient's diagnosis, severity of symptoms, and preference. In general, severe depressive illnesses, particularly those that are recurrent, will require a combination of treatments for the best outcome.

If you are feeling depressed, tell someone about your symptoms. Speak with a doctor, nurse, psychologist, social worker, or employee assistance professional. Asking for help takes courage, but it can make all the difference.

Where to get more information

National Institute of Mental Health
Public Inquiries

6001 Executive Boulevard, Room 8184, MSC 9663
Bethesda, MD 20892-9663
Toll-Free: 1-866-227-NIMH

E-mail: nimhinfo@nih.gov

Web site: <http://www.nimh.nih.gov>

Department of Health & Human Services
National Institutes Of Health
National Institute of Mental Health
NIH Publication No. 03-5300

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WOMEN & DEPRESSION

Everyone occasionally feels blue or sad, but these feelings are usually fleeting and pass within a couple of days. When a woman has a depressive disorder, it interferes with daily life and normal functioning, and causes pain for both the woman with the disorder and those who care about her. Depression is a common but serious illness, and most who have it need treatment to get better.

Depression affects both men and women, but more women than men are likely to be diagnosed with depression in any given year. Efforts to explain this difference are ongoing, as researchers explore certain factors (*biological, social, etc.*) that are unique to women.

What are the basic signs and symptoms of depression?

Women with depressive illnesses do not all experience the same symptoms. In addition, the severity and frequency of symptoms, and how long they last, will vary depending on the individual and her particular illness. Signs and symptoms of depression include:

- Persistent sad, anxious or “empty” feelings
- Feelings of hopelessness and/or pessimism
- Irritability, restlessness, anxiety
- Feelings of guilt, worthlessness and/or helplessness
- Loss of interest in activities or hobbies once pleasurable, including sex
- Fatigue and decreased energy
- Difficulty concentrating, remembering details and making decisions
- Insomnia, waking up during the night, or excessive sleeping
- Overeating, or appetite loss
- Thoughts of suicide, suicide attempts
- Persistent aches or pains, headaches, cramps or digestive problems that do not ease even with treatment

What causes depression in women?

Scientists are examining many potential causes for, and contributing factors to, women’s increased risk for depression. It is likely that genetic, biological, chemical, hormonal, environmental, psychological, and social factors all intersect to contribute to depression.

Menopause

Hormonal changes increase during the transition between pre-menopause to menopause. While some women may transition into menopause without any problems with mood, others experience an increased risk for depression. This seems to occur even among women without a history of depression. However, depression becomes less common for women during the post-menopause period.

Stress

Stressful life events such as trauma, loss of a loved one, a difficult relationship or any stressful situation—whether welcome or unwelcome—often occur before a depressive episode. Additional work and home responsibilities, caring for children and aging parents, abuse, and poverty also may trigger a depressive episode. Evidence suggests that women respond differently than men to these events, making them more prone to depression. In fact, research indicates that women respond in such a way that prolongs their feelings of stress more so than men, increasing the risk for depression. However, it is unclear why some women faced with enormous challenges develop depression, and some with similar challenges do not.

What illnesses often coexist with depression in women?

Depression often coexists with other serious medical illnesses such as heart disease, stroke, cancer, HIV/AIDS, diabetes, Parkinson’s disease, thyroid problems and multiple sclerosis, and may even make symptoms of the illness worse. Studies have shown that both women and men who have depression in addition to a serious medical illness tend to have more severe symptoms of both illnesses. They also have more difficulty adapting to their medical condition, and more medical costs than those who do not have coexisting depression. Research has shown that treating the depression along with the coexisting illness will help ease both conditions.

How is depression diagnosed and treated?

Depressive illnesses, even the most severe cases, are highly treatable disorders. As with many illnesses, the earlier that treatment can begin, the more effective it is and the greater the likelihood that a recurrence of the depression can be prevented.

The first step to getting appropriate treatment is to visit a doctor. Certain medications, and some medical conditions such as viruses or a thyroid disorder, can cause the same symptoms as depression. In addition, it is important to rule out depression that is associated with another mental illness called bipolar disorder. A doctor can rule out these possibilities by conducting a physical examination, interview, and/or lab tests, depending on the medical condition. If a medical condition and bipolar disorder can be ruled out, the physician should conduct a psychological evaluation or refer the person to a mental health professional.

Once diagnosed, a person with depression can be treated with a number of methods. The most common treatment methods are medication and psychotherapy.

How can I help a friend or relative who is depressed?

If you know someone who has depression, the first and most important thing you can do is to help her get an appropriate diagnosis and treatment. In addition, you can also:

- Offer emotional support, understanding, patience and encouragement.
- Engage her in conversation, and listen carefully.
- Never disparage feelings she expresses, but point out realities and offer hope.
- Never ignore comments about suicide, and report them to your friend’s or relative’s therapist or doctor.
- Invite your friend or relative out for walks, outings and other activities. Keep trying if she declines, but don’t push her to take on too much too soon. Although diversions and company are needed, too many demands may increase feelings of failure.
- Remind her that with time and treatment, the depression will lift.

How can I help myself if I am depressed?

You may feel exhausted, helpless and hopeless. It may be extremely difficult to take any action to help yourself. But it is important to realize that these feelings are part of the depression and do not reflect actual circumstances. As you recognize your depression and begin treatment, negative thinking will fade. In the meantime:

- Engage in mild activity or exercise. Go to a movie, a ballgame, or another event or activity that you once enjoyed. Participate in religious, social or other activities. Set realistic goals for yourself.
- Break up large tasks into small ones, set some priorities and do what you can as you can.
- Try to spend time with other people and confide in a trusted friend or relative. Try not to isolate yourself, and let others help you.
- Expect your mood to improve gradually, not immediately. Do not expect to suddenly “snap out of” your depression. Often during treatment for depression, sleep and appetite will begin to improve before your depressed mood lifts.
- Postpone important decisions, such as getting married or divorced or changing jobs, until you feel better. Discuss decisions with others who know you well and have a more objective view of your situation.
- Be confident that positive thinking will replace negative thoughts as your depression responds to treatment.

What if I or someone I know is in crisis?

- Women are more likely than men to attempt suicide. If you are thinking about harming yourself or attempting suicide, tell someone who can help immediately.
- Call your doctor.
- Call 911 for emergency services.
- Go to the nearest hospital emergency room.
- Call the toll-free, 24-hour hotline of the National Suicide Prevention Lifeline at 1-800-273-TALK

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To see the specific list, however, of each author, or group of authors, who contributed to this article, please visit the web page listed.

CAREGIVING AND DEPRESSION

Could the sadness, loneliness or anger you feel today be a warning sign of depression? It's possible. It is not unusual for caregivers to develop mild or more serious depression as a result of the constant demands they face in providing care.

Caregiving does not cause depression, nor will everyone who provides care experience the negative feelings that go with depression. But in an effort to provide the best possible care for a family member or friend, caregivers

often sacrifice their own physical and emotional needs and the emotional and physical experiences involved with providing care can strain even the most capable person. The resulting feelings of anger, anxiety, sadness, isolation, exhaustion—and then guilt for having these feelings—can exact a heavy toll.

Everyone has negative feelings that come and go over time, but when these feelings become more intense and leave caregivers totally drained of energy, crying frequently or easily angered by their loved one or other people, it may well be a warning sign of depression. Concerns about depression arise when the sadness and crying don't go away or when those negative feelings are unrelenting.

Unfortunately, feelings of depression are often seen as a sign of weakness rather than a sign that something is out of balance. Comments such as “snap out of it” or “it's all in your head” are not helpful, and reflect a belief that mental health concerns are not real. Ignoring or denying your feelings will not make them go away.

Early attention to symptoms of depression through exercise, a healthy diet, positive support of family and friends, or consultation with a trained health or mental health professional may help to prevent the development of a more serious depression over time.

Symptoms of Depression

People experience depression in different ways. Some may feel a general low-level sadness for months, while others suffer a more sudden and intense negative change in their outlook. The type and degree of symptoms vary by individual and can change over time. Consider these common symptoms of depression. Have you experienced any of the following for longer than two weeks?

- A change in eating habits resulting in unwanted weight gain or loss
- A change in sleep patterns—too much sleep or not enough
- Feeling tired all the time
- A loss of interest in people and/or activities that once brought you pleasure
- Becoming easily agitated or angered
- Feeling that nothing you do is good enough
- Thoughts of death or suicide, or attempting suicide
- Ongoing physical symptoms that do not respond to treatment, such as headaches, digestive disorders and chronic pain.

Special Caregiver Concerns

What do lack of sleep, dementia and whether you are male or female have in common? Each can contribute in its own way to a caregiver's increased risk for depression.

Dementia and Care

Researchers have found that a person who provides care for someone with dementia is twice as likely to suffer from depression as a person providing care for someone without dementia. The more severe the case of dementia such as that caused by Alzheimer's disease, the more likely the caregiver is to experience depression. It is critical for caregivers, especially in these situations, to receive consistent and dependable support.

Caring for a person with dementia can be all consuming. It is different from other types of caregiving. Not only do caregivers spend significantly more hours per week providing care, they report more employment problems, personal stress, mental and physical health problems, less time to do the things they enjoy, less time to spend with other family members, and more family conflict than nondementia caregivers. As stressful as the deterioration of a loved one's mental and physical abilities may be for the caregiver, dealing with dementia-related behavior is an even bigger contributor to developing symptoms of depression. Dementia-related symptoms such as wandering, agitation, hoarding and embarrassing conduct makes every day challenging and makes it harder for a caregiver to get rest or assistance in providing care.

Women experience depression at a higher rate than men. Women, primarily wives and daughters, provide the majority of caregiving. In the United States, approximately 12 million women experience clinical depression each year, at approximately twice the rate of men. A National Mental Health Association survey on the public's attitude and beliefs about clinical depression found that more than one-half of women surveyed still believe it is "normal" for a woman to be depressed during menopause.

The study also found that many women do not seek treatment for depression because they are embarrassed or in denial about being depressed. In fact, 41% of women surveyed cited embarrassment or shame as barriers to treatment.

Men who are caregivers deal with depression differently. Men are less likely to admit to depression and doctors are less likely to diagnose depression in men. Men will more often "self treat" their depressive symptoms of anger, irritability or powerlessness with alcohol or overwork. Although male caregivers tend to be more willing than female caregivers to hire outside help for assistance with home care duties, they tend to have fewer friends to confide in or positive activities outside the home. The assumption that depressive symptoms are a sign of weakness can make it especially difficult for men to seek help.

Lack of sleep contributes to depression. While sleep needs vary, most people need eight hours a day. Loss of sleep as a result of caring for a loved one can lead to serious depression. The important thing to remember is that even though you may not be able to get your loved one to rest throughout the night, you can arrange to get much needed sleep. Hiring a respite worker to be with your loved one while you take a nap or finding a care center or scheduling a stay over with another family member for a few nights are ways to keep your caregiving commitment while getting the sleep you need.

Depression can persist after placement in a care facility. Making the decision to move a loved one to a care center is very stressful. While many caregivers are finally able to catch up on much needed rest, loneliness, guilt and monitoring the care a loved one receives in this new location can add new stress. Many caregivers feel depressed at the time of placement and some continue to feel depressed for a long time after.

People assume that once caregiving is over, the stress from providing hands-on care will go away. Yet, researchers found that even three years after the death of a spouse with dementia, some former caregivers continued to experience depression and loneliness. In an effort to return their life to normal, former caregivers may need to seek out help for depression as well.

What to Do If You Think You Have Depression

Depression deserves to be treated with the same attention afforded any other illness, such as diabetes or high blood pressure. If you feel uncomfortable using the term depression, tell the professional that you are "feeling blue" or "feeling down." The professional will get the message. The important thing is to seek help.

Those with chronic illnesses also may suffer from depression. If you suspect this is the case with your loved one, look for an opportunity to share your concern with him or her. If they are reluctant to talk about it with you, encourage a trusted friend to talk with them or consider leaving a message for their doctor regarding your concern prior to their next appointment.

How is Depression Treated?

The first step to getting the best treatment for depression is to meet with a mental health professional such as a psychiatrist, psychologist, or social worker. At the same time, schedule a physical exam with your doctor. Certain medications, as well as some medical conditions such as viral infection, can cause the same symptoms as depression, and can be evaluated by your physician during an exam. The exam should include lab tests and an interview that tests for mental status to determine if speech, memory or thought patterns have been affected.

Although it's not unusual for a physician to prescribe antidepressant medication, medication alone may not be the most effective treatment for depression. The guidance of a mental health professional throughout your treatment is strongly recommended. The therapist or counselor will listen to your concerns, screen you for symptoms of depression and assist you in setting up an appropriate course of treatment.

One way to find a professional is to ask a friend for the name of someone they know and trust. You may also find someone by asking your minister or rabbi, your doctor, or, if you are employed, you may check your employer's health insurance provider list or EAP program. In addition, national organizations can provide contact information for mental health professionals in your community. It is important to trust and feel comfortable with the professional you see. It is not uncommon to request a free introductory phone or in-person meeting to help determine if the professional is the right match for your particular needs and style. It is appropriate to clarify what the cost will be, how much your insurance will pay and how many scheduled sessions you should expect to have with the mental health therapist. Any treatment should be evaluated regularly to ensure that it continues to contribute towards your improved health and growth.

Strategies to Help Yourself

Depressive disorders can make one feel exhausted, helpless and hopeless. Such negative thoughts and feelings make some people feel like giving up. It is important to realize that these negative views are part of the depression and may not accurately reflect the situation. The National Institute of Mental Health offers the following recommendations for dealing with depression:

- Set realistic goals in light of the depression and assume a reasonable amount of responsibility.
- Break large tasks into small ones, set some priorities, and do what you can as you can.
- Try to be with other people and to confide in someone; it is usually better than being alone and secretive.
- Participate in activities that may make you feel better, such as mild exercise, going to a movie or ballgame, or attending a religious, social or community event.
- Expect your mood to improve gradually, not immediately. Feeling better takes time.
- It is advisable to postpone important decisions until the depression has lifted. Before deciding to make a significant transition—change jobs, get married or divorced—discuss it with others who know you well and have a more objective view of your situation.
- People rarely “snap out of” a depression. But they can feel a little better day-by-day.

- Remember, positive thinking will replace the negative thinking that is part of the depression. The negative thinking will be reduced as your depression responds to treatment.
- Let your family and friends help you.
- Direct assistance in providing care for your loved one, such as respite care relief, as well as positive feedback from others, positive self-talk, and recreational activities are linked to lower levels of depression. Look for classes and support groups available through caregiver support organizations to help you learn or practice effective problem-solving and coping strategies needed for caregiving. For your health and the health of those around you, take some time to care for yourself.

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Resources

Family Caregiver Alliance
180 Montgomery Street, Ste. 900, San Francisco, CA 94104
(415) 434-3388 (415) 434-3388
(800) 445-8106 (800) 445-8106

Web Site: www.caregiver.org

E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy.

Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

For residents of the greater San Francisco Bay Area, FCA provides direct family support services for caregivers of those with Alzheimer's disease, stroke, head injury, Parkinson's and other debilitating disorders that strike adults.

Excerpts of Family Caregiver Alliance “Caregiving and Depression” fact sheet used with permission. For more information, visit www.caregiver.org or call (800) 445-8106.

SUICIDE

Suicide is the process of purposely ending one's own life. There are many religious and social stigmas associated with suicide, but the effects of suicidal behavior or completed suicide are often devastating on family and friends.

Suicide is considered a public health problem in the United States as more than 32,000 people kill themselves each year and more than 395,000 people with self-inflicted injuries are treated in emergency rooms annually.

Suicide, by definition, is fatal, but those who attempt suicide and live may have serious injuries like broken bones, brain damage or organ failure. Also, persons who survive a suicide attempt often have depression and other mental health problems.

Suicide affects the whole community. Sixty percent of all people in the U.S. have experienced the suicide death of someone they know. Family and friends of people who die by suicide often feel shock, anger, guilt or depression. The medical costs and lost wages associated with suicide also take their toll on the community.

It is important to be aware of the risk factors for suicide and the signs and symptoms that a suicide crisis may be imminent.

Common myths about suicide

Myth: "People who talk about suicide won't really do it."

Fact: Almost everyone who commits suicide has given some clue or warning. For every ten people who kill themselves, eight have given definite clues to their intentions. Do not ignore suicide threats. Statements like "You'll be sorry when I'm dead," or "I can't see any way out", no matter how casually or jokingly said, may indicate serious suicidal feelings.

Myth: "Anyone who tries to kill themselves must be crazy."

Fact: Most suicidal people are not psychotic or insane. They must be upset, grief-stricken, depressed, or despairing, but extreme distress and emotional pain are not necessarily signs of mental illness.

Myth: "If a person is determined to kill themselves, nothing is going to stop them."

Fact: Even the most severely depressed person has mixed feelings about death, wavering until the very last moment between wanting to live and wanting to die. Most suicidal people do not want death; they want the pain to stop. The impulse to end it all, however overpowering, does not last forever.

Myth: "People who commit suicide are people who were unwilling to seek help."

Fact: Studies of suicide victims have shown that more than half had sought medical help within six months before their deaths.

Myth: "Talking about suicide may give someone the idea."

Fact: You don't give a suicidal person morbid ideas by talking about suicide. The opposite is true-bringing up the subject of suicide and discussing it openly is one of the most helpful things you can do.

Myth: "People who complete suicide always leave notes."

Fact: Most people don't leave notes.

Myth: "Most suicides occur during the holidays."

Fact: Most suicides occur in the springtime, a time of renewal except for those who feel they have nothing to live for.

Myth: "Once a person has attempted suicide, he/she is unlikely to try again."

Fact: People who have attempted suicide are very likely to try again. In fact, 80% of people who die by suicide have made at least one previous attempt.

Be Aware of the Warning Signs. The American Association of Suicidology has developed an easy mnemonic to remember the warning signs:

IS PATH WARM?

Ideation Substance Abuse Purposelessness Anxiety Trapped Hopelessness Withdrawal Anger Recklessness Mood Changes

Seek Professional Help

Seek help as soon as possible by contacting a mental health professional or call our crisis helpline at (972) 233-2233 for help should you witness, hear or see someone exhibiting the warning signs for suicide.

Other Ways to Help

Talk openly, directly and matter-of-factly about suicide. It is a myth that talking about suicide will cause someone to attempt suicide.

- Be willing to listen and accept expressions of feelings.
- Be non-judgmental. Don't lecture on the value of life.
- Get involved and show interest and support.
- Never dare someone.
- Don't act shocked.
- Don't be sworn to secrecy. Seek support.
- Offer hope that alternatives are available but don't be glib.
- Take action. Remove means such as guns or pills.

Call our crisis line at (972) 233-2233 or the National Suicide Prevention Lifeline at 1 (800) 273-TALK (8255) for help.

Resources for suicide (links)

National Strategy for Suicide Prevention – www.mentalhealth.samhsa.gov,

National Suicide Prevention Lifeline – www.suicidepreventionlifeline.org,

American Association of Suicidology – www.suicidology.org,

American Foundation for Suicide Prevention – www.afsp.org,

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

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Medical Updates

FDA APPROVES BOTOX TO TREAT SPECIFIC FORM OF URINARY INCONTINENCE

The U.S. Food and Drug Administration today approved Botox (onabotulinumtoxinA) injection to treat urinary incontinence in people with neurologic conditions such as spinal cord injury and multiple sclerosis who have overactivity of the bladder.

Uninhibited urinary bladder contractions in people with some neurological conditions can lead to an inability to store urine. Current management of this condition includes medications to relax the bladder and use of a catheter to regularly empty the bladder.

The treatment consists of Botox being injected into the bladder resulting in relaxation of the bladder, an increase in its storage capacity and a decrease in urinary incontinence. "Urinary incontinence associated with neurologic conditions can be difficult to manage," said George Benson, deputy director, Division of Reproductive and Urologic Products. "Botox offers another treatment option for these patients."

Injection of the bladder with Botox is performed using cystoscopy, a procedure that allows a doctor to visualize the interior of the bladder. Cystoscopy may require general anesthesia. The duration of the effect of Botox on urinary incontinence in patients with bladder overactivity associated with a neurologic condition is up to 10 months.

The effectiveness of Botox to treat this type of incontinence was demonstrated in two clinical studies involving 691 patients. The patients had urinary incontinence resulting from spinal cord injury or multiple sclerosis. Both studies showed statistically significant decreases in the weekly frequency of incontinence episodes in the Botox group compared with placebo.

In addition to its use to improve the appearance of facial frown lines, Botox also is FDA-approved to treat chronic migraine headaches, certain kinds of muscle stiffness and contraction, severe underarm sweating, abnormal twitch of the eyelid and a condition in which the eyes are not properly aligned.

The most common adverse reactions observed following injection of Botox into the bladder were urinary tract infection and urinary retention. Those who develop urinary retention after Botox treatment may require self-catheterization to empty the bladder.

Botox is marketed in the United States by Allergan Inc., of Irvine, Calif.

The FDA, an agency within the U.S. Department of Health and Human Services, protects the public health by assuring the safety, effectiveness, and security of human and veterinary drugs, vaccines and other biological products for human use, and medical devices. The agency also is responsible for the safety and security of our nation's food supply, cosmetics, di-

etary supplements, products that give off electronic radiation, and for regulating tobacco products.

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301-796-2807

CAUSE OF ALS IS FOUND

Researchers at Northwestern University say they have discovered a common cause behind the mysterious and deadly affliction of amyotrophic lateral sclerosis, or Lou Gehrig's disease, that could open the door to an effective treatment. Dr. Teepu Siddique, a neuroscientist with Northwestern's Feinberg School of Medicine whose pioneering work on ALS over more than a quarter-century fueled the research team's work, said the key to the breakthrough is the discovery of an underlying disease process for all types of ALS. The discovery provides an opening to finding treatments for ALS and could also pay dividends by showing the way to treatments for other, more common neurodegenerative diseases such as Alzheimer's, dementia and Parkinson's, Siddique said. The Northwestern team identified the breakdown of cellular recycling systems in the neurons of the spinal cord and brain of ALS patients that results in the nervous system slowly losing its ability to carry brain signals to the body's muscular system.

Without those signals, patients gradually are deprived of the ability to move, talk, swallow and breathe.

"This is the first time we could connect (ALS) to a clear-cut biomedical mechanism," Siddique said. "It has really made the direction we have to take very clear and sharp. We can now test for drugs that would regulate this protein pathway or optimize it, so it functions as it should in a normal state."

The announcement of the breakthrough is in Monday's issue of the research journal *Nature*. The paper lists 23 contributing scientists, including the lead authors, Northwestern neurological researchers Han-Xiang Deng and Wenjie Chen, and Siddique as senior author.

Amelie Gubitz, a research program director at the National Institute of Neurological Disorders and Stroke, said the Northwestern research is a big step forward in efforts worldwide to conquer ALS. "You need to understand at the cellular level what is going wrong," said Gubitz. "Then you can begin to design drugs. "ALS is a complicated problem, and Dr. Siddique's research adds a big piece to the puzzle that gives us important new insights."

A variety of proteins perform different functions within cells, and Deng and Chen led research that discovered a key protein, ubiquilin2, in the ALS mystery. Ubiquilin2 in spinal and brain system cells is supposed to repair or dispose of other proteins

as they become damaged. The researchers discovered a breakdown of this function in ALS patients. When Ubiquilin2 is unable to remove or repair damaged proteins, the damaged proteins begin to pile up in the cells, eventually blocking normal transmission of brain signals in the spinal cord and brain, leading to paralysis.

Excerpt from: *Chicago Tribune* – August 22, 2011
William Mullen, Tribune Report
Keri Wiginton

To read article in its entirety, please visit: <http://articles.chicagotribune.com/2011>

PRESS RELEASE by Labspaces

STUDY OFFERS NEW CLUES ABOUT HEREDITARY SPASTIC PARAPLEGIA

Friday, July 8, 2011

New research from Rice University and Italy's Eugenio Medea Scientific Institute is yielding clues about hereditary spastic paraplegia (HSP), a group of inherited neurological disorders that affect about 20,000 people in the United States. A study in the July 5 issue of the Proceedings of the National Academy of Sciences offers the first detailed account of the biochemical workings of atlastin, a protein produced by one of the genes linked to HSP.

The primary symptoms of HSP are progressive spasticity and weakness of the leg and hip muscles. This results from the slow degeneration of the nerves that carry signals from the spinal column to the legs, feet and toes. While scientists know that HSP can result from more than two dozen different genetic mutations, they don't know how the mutations cause nerve degeneration.

"We discovered a couple of years ago that atlastin plays a key role in building and maintaining an important internal compartment of healthy cells called the endoplasmic reticulum," said Rice biochemist James McNew, lead co-author of the new study. "HSP is known to primarily affect long nerve cells that can stretch from the lower back all the way to the base of the leg. It appears that atlastin plays a particularly crucial role in maintaining the health of these cells, and we want to know why."

McNew, associate professor of biochemistry and cell biology at Rice, and Andrea Daga, a scientist at the Medea Institute, determined in 2009 that atlastin was one of the rare breed of proteins that can cause membrane fusion.

"Membrane fusion is a fundamental process involved in many cell functions, but only a few proteins can initiate it," McNew said. "Until 2009, we thought all membrane fusion proteins operated in the same basic way. Atlastin was completely different because it's an enzyme that utilizes chemical energy to drive fusion. We really had to start from scratch to determine how it worked."

Membranes are both the brick walls and the zip-lock bags of microbiology. Every living cell is encased in a water-tight membrane of fatty acids, and all of the cell's interactions with the outside world are mediated by what can and cannot pass through that membrane. When a virus invades a healthy cell, it uses membrane fusion. When a sperm fertilizes an egg, it uses membrane fusion. Membranes are also used inside the cell, where they serve as biochemical reaction chambers, as cargo containers and as pipelines.

To find out how atlastin initiates membrane fusion, McNew, Daga and colleagues conducted experiments involving the fruit-fly version of atlastin, which is remarkably similar to the version found in humans. By selectively disabling portions of the protein and examining how those modifications affected atlastin's ability to promote membrane fusion in the test tube and cell cultures, the team gradually built a picture of how atlastin works. They found that pairs of atlastin proteins, each of which is anchored in a separate membrane, can bind to one another when both partners are functional enzymes. That action draws the separated membranes together and allows fusion to occur. Additionally, they found that a small piece near the end of atlastin was required for fusion activity.

"Atlastin has a fairly short tail, which protrudes from the site where the protein is anchored into the membrane," Daga said. "When we deleted this tail, we found that the protein could not stimulate membrane fusion, even when the two copies bound together normally."

McNew said prior gene sequencing studies have shown that some HSP patients have genetic mutations that result in defects in this critical tail region of the atlastin protein.

"This study, as well as work by others, suggests the area of the cell where atlastin promotes membrane fusion, the endoplasmic reticulum, is a good target for future studies into the causes of HSP," said McNew, a faculty investigator at Rice's BioScience Research Collaborative.

Rice University: <http://media.rice.edu>

Author: Unknown

Thanks to Rice University for this article (as posted on LabSpaces)

This press release was posted online by LabSpaces at: www.labspaces.net/111827/Study_offers_new_clues_about_hereditary_spastic_paraplegia

A variation of this article also found at: Rice University (2011, July 8). New clues about hereditary spastic paraplegia. ScienceDaily. Retrieved September 14, 2011, from <http://www.sciencedaily.com/releases/2011/07/110708124544.htm>

Journal Reference: T. J. Moss, C. Andreazza, A. Verma, A. Daga, J. A. McNew. Membrane fusion by the GTPase atlastin requires a conserved C-terminal cytoplasmic tail and dimerization through the middle domain. Proceedings of the National Academy of Sciences, 2011; 108 (27): 11133 DOI: 10.1073/pnas.1105056108

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*Colorado Connection
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*Texas Patient Connection Luncheon
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