

the challenger

A Publication of the NATIONAL ALLIANCE for the MENTALLY ILL in Buffalo & Erie County

vol. 20, no. 7
November-December 2004

Mark Your Calendar

November

NAMI Business Meeting, Thursday, November 4th, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. All NAMI members are welcome!

NAMI Family Meeting, Thursday, November 11th, St. Paul's Evangelical Lutheran Church, 4007 Main Street, Amherst. Library and Hospitality Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: Ann Birmingham, Attorney-at-Law, on Special Needs Trusts

December

NAMI Business Meeting, Thursday, December 2nd, 7:30 PM, NAMI Hope House, 432 Amherst Street, Buffalo. Join your Executive Board for an informative evening.

NAMI Holiday Party, Thursday, December 9th, 7:00 PM, St. Paul's Lutheran Church, 4007 Main Street, Amherst. Bring a plate of holiday goodies to share and enjoy a night of respite and fellowship with NAMI friends.

NAMI "Christmas is for Kids" Wrapping Session, Saturday, December 11th, 10 AM til we're done, NAMI Hope House, 432 Amherst Street, Buffalo. Bring a pair of scissors. Volunteers needed!

January

No NAMI Business Meeting!

NAMI Family Meeting, Thursday, January 13th, Barbara Burns and Kathy Brinkworth, on the Multi-family Psychoeducation Project. Library and hospitality hour: 7:00 PM, General Meeting: 7:30 PM, St. Paul's Evangelical Lutheran Church, 4007 Main Street.

NAMI Support Group for Families, Wednesday, January 26, Hope House, 432 Amherst Street, Buffalo. 7:30 PM

February

NAMI Business Meeting, Thursday, February 3rd, 7:30 PM, NAMI's Hope House, 432 Amherst Street, Buffalo.

NAMI Family Meeting, Thursday, February 10th, St. Paul's Evangelical Lutheran Church, 4007 Main Street. Library and Hospitality Hour: 7:00 PM. General Meeting: 7:30 PM. Guest speaker: To Be Announced.

NAMI Support Group for Families, Wednesday, February 24th, Hope House, 432 Amherst Street, Buffalo. 7:30 PM

NAMI's Christmas is for Kids



NAMI families bear heavy burdens with great courage and grace—the grief of seeing a loved son or daughter move from the sunlight and bright promise of youth to the shadows of serious mental illness—the worry and fear created by the illness and a treatment system unresponsive to their concerns—the fear of the future and what will happen to their child when the parents are gone.

Yet, in spite of their concerns and anxiety for their own, at holiday time, NAMI families reach out to children and teens who are just at the beginning of their own uphill journey into mental illness and adulthood.

NAMI's Christmas is for Kids project provides holiday gifts and birthday remembrances for nearly 600 mentally ill and emotionally disturbed young people living in residential placement, foster care, or, often, with a grandmother or aunt when their own families are broken. Kids living at home are often in terribly fragile or marginal circumstances.

Mothers on crack. Dads in jail. A mom who is seriously ill herself. Dad gone. There's little money for Christmas delights or birthday treats. So NAMI families step up to the plate and on December 11th, will gather to sort and wrap a treasure-trove of delights for children whose only Christmas will likely be the gifts from our hands to theirs.

Please join us for our wrapping session—bring a gift if you can or make a special contribution to the NAMI Christmas is for Kids fund. We'd be grateful especially for gifts for teens such as sweatshirts, teen underwear, cosmetics and hair-care products, games, winter coats and jackets, bedsheets, boys wallets, sports equipment, boxed crafts sets, theater passes and gift certificates. (*All items should be new, please!*)

See you on the 11th.

Mailing Address • 264 Hamilton Drive • Buffalo, NY 14226 • 716 839-0548
HOPE HOUSE • 432 Amherst Street • Buffalo, NY 14207 • 716 877- 9415
www.namibuffalo.org

UB Medical School Department of Psychiatry Grand Rounds

- Nov. 12
Friday
10:30 AM
BPC** **"Neurobiology of Dopamine Receptor: Implications for Psychosis Prevention"** John Kane, MD and Neil Richtand, MD, PhD.
- Nov. 19
Friday
10:30 AM
BPC** **"How to Interpret Psychiatric Research"** Steven L. Dubovsky, MD, Chairman, SUNY Buffalo Department of Psychiatry.
- Dec. 10
Friday
10:30 AM
BPC** **"Antipsychotic-induced Metabolic Disturbances: exploring the Mechanisms,"** Xiaoduo Fan, MD
- Dec. 17
Friday
10:30 AM
BPC** **"Criminalization of the Mentally Ill"** Mr. Andrew Skolnick, Exec. Dir. of the Commission for Scientific Medicine and and Mental Health, Center for Inquiry
- Jan. 7
Friday
10:30 AM
BPC** **"Being From the Inside Out: Reflections on Dance and Psychoanalysis"** Emily Ets-Hokin, PhD, Clinical Psychologist-psychoanalyst

NAMI members are invited to attend Grand Rounds presentations.

Thanks...

To **Wanda Haak, Mickey Delaney,** and **Nancy Smith** for many hours addressing our Anniversary Celebration invitations

To **Miriam Becker** and **Rosemary Donnelly** for packing up and unpacking our library materials for the move to St. Paul's Church; and to **Ken Olsen** for hauling the boxes and boxes of books and brochures to make them available to our members.

To **Norine Thibault** for sending notices every month to the media of the schedule of our monthly meetings.

To the **CSK Foundation** for their donation of \$5,000—the proceeds of their 2003 and 2004 golf tournaments—to further the work of NAMI Buffalo & Erie County.

To **Radhika Iyer** for her many volunteer hours as we begin the preparations for the next edition of The Mind Matters.

To the **many volunteers** who served as the Committee for our 20th Anniversary Celebration: **Suzanne Kirkland** for beautiful flower arrangements for each table; the hospitality folks, and, always to **President Mary Kirkland** and **husband Jim**, as well as **Sherwin Greenberg** for designing our beautiful invitations.

Spotlight on Health

Saturdays 8:00-8:30 a. m.

Hosted by

Tom McNulty

On

WECK-AM 1230

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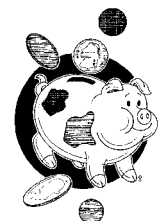
Success Stories, Inc.

If You're a Tops Shopper...

Please remember to save your grocery and pharmacy tapes for NAMI Buffalo. Tops provides a rebate based on the dollar amount of collected tapes. Either bring them in with you to the monthly NAMI meeting or mail them to:

Barbara Rex
4129 Wildwood Dr.
Williamsville, NY 14221

Thanks!



Letters...

After our initial conversation several days ago, and the numbness of what has happened has worn off with extreme sadness I find the ability to write this letter.

My father, Patrick Manahr was admitted to ECMC abler attempting suicide by an overdose and was a patient from June 16 to July 20, 2004. From my understanding, lie had been suffering from an acute case of depression which he lived with for many years and which was under control until several months ago.

Sadly, my father died on August 12, 2004 when he committed suicide by hanging himself.

I have many concerns about my father's hospitalization, but the most significant one involves a conversation I had with Cheryl Nowicki, who was consulted regarding his housing situation.

My father was terrified to return to his home and be alone. Cheryl met with my father on several occasions to discuss housing options, and at my suggestion staff arranged a site visit to help alleviate my father's anxiety about living in supportive housing. After the visit, Cheryl called to inform me that in her opinion my father was not appropriate for this housing alternative since he was adequately able to function on his own, as demonstrated by showering, brushing his teeth and getting dressed.

She urged me to refrain from helping him because my father would "exhaust", me and stated that I could not "SAVE HIM" an expression reiterated several times throughout our conversation. Cheryl added that she felt my father's first suicide attempt was primarily intended to get attention, Whenever I raised a question or concern or when I asked her about my father's diagnosis, she stated that in her opinion my father's problem was a personality disorder, not bipolar or serious depression. She stated that my father could be discharged at any point because staff could no longer do anything for him. She felt that he could go back into his home, pick himself up "by his own bootstraps" and that she or other staff would no longer "jump through hoops" for him.

In addition, she had a similar conversation with my father. After this conversation, he acknowledged that this conversation increased his anxiety since it made him feel his anxiety

and hopelessness could only be cured by pulling himself together, which he knew he could not do.

Cheryl, in so many words you told my father and me to give up HOPE and let him fend for himself.

The guilt and pain that I have in this whole situation is that despite my better judgment I listened. I was afraid to come forward to express my concern because I didn't want my father or other family members who may be hospitalized in the future to be labeled as difficult or challenging. I didn't want to "buck" the system, I was only asking for help. My conversation with Cheryl made me withdraw from other interactions with professionals because I left that my input was no longer necessary.

I'm no longer afraid of being a difficult, demanding family member by asking staff to "jump through hoops". My father is no longer here to be helped or have these hoops jumped through, but I can't live to know that these interactions will continue to happen without change. I have many questions that need to be answered regarding therapeutic programs that are offered to patients throughout the day, continuity and communication from staff to patient to family and other concerns that save the little dignity that marry patients hold on to us they are struggling to maintain their hope.

I'm not writing this letter to blame, but only create awareness of the difficulty that not only patients, but families have in struggling to understand a family member with mental illness. My only hope is that staff can closely listen to my concerns before jumping to conclusions, blaming or becoming angry,

Erin K. Stievater

In the News...

State should be investing in people, not buildings

So Gov. George Pataki giveth and then taketh away. One day he's shoveling \$100 million to Buffalo for the very dubious purpose of saving the crumbling old Richardson buildings at the Buffalo Psychiatric Center. A few days later, he vetoes \$52 million to move the University at Buffalo School of Pharmacy, a far more promising project. Does anyone really know how much money "architectural tourism" generates as a return on investment? How many tourists would have to visit Buffalo for how many decades to reap a repayment on \$100 million?

In the meantime, Pataki has vetoed \$10 million in the budget for improving the lives of mentally ill people living in horrendous adult homes, the last place left for nearly 14,000 New Yorkers who would have once resided in the state's psychiatric centers. State lawmakers shut those doors and closed their eyes to the misery and suffering resulting from the closure of those beds.

Every mentally ill person could have a decent, safe place to live if the governor were willing to make an investment in human lives rather than a pile of bricks and mortar.

*Lynne M. Shuster
Coordinator, National Alliance for the
Mentally Ill in Buffalo and Erie County
September 7, 2004
The Buffalo News*



In the News...

ECMC is in Desperate Need of a Thorough Cleaning

Last week, I accompanied my wife to Erie County Medical Center for her presurgical admission processing and testing. All of the personnel were super and did a good job.

As we sat by the admission clerk's desk, I looked at the narrow space between her desk and her cubical wall. It was filthy, with more than a year's accumulation of dust, lint, spider webs and paper scraps. Then I looked at the other end of her desk, which was up against a post, and found the same thing. Completely appalled, I looked around the edges of the room where the walls of the cubical meet the floor. There was more dirt - years of dirt - around the entire space. I asked the clerk about the absence of housekeeping standards, and she said that she agreed, and hoped that I would complain. In the waiting area, I saw more of the same. I didn't go into the examination room, but my wife said that it also was dirty. She had her surgery this week. Fortunately, the housekeeping on the upper floors was very good, and the nurses were most helpful.

However, if ECMC were a military hospital and I were an inspecting general who observed the conditions on the ground floor and first floor, I could guarantee courts martial for many individuals. I didn't pay much attention to the recent News stories about a change in leadership at ECMC, but I have now seen the evidence that the new guy had better get on the ball.

*Jerome Miller
August 27, 2004
The Buffalo News*

The Future Fund

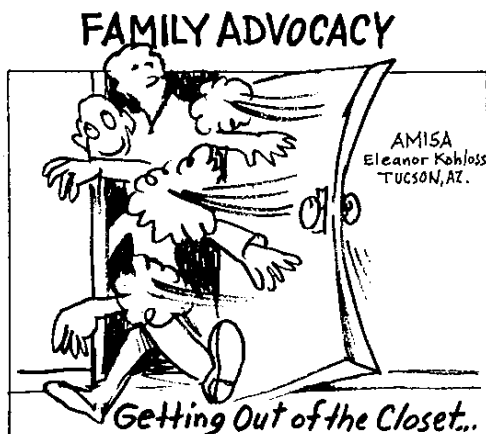
*Please make your
contribution today!*

In Brief...

Commissioner of Mental Health **Michael Weiner** has been promoted to Commissioner of Social Services which under a County reorganization plan will now include the Department of Mental Health.

The Commission on the Quality of Care (a state-wide watchdog agency) has an excellent newsletter which is now published only on the Web. It can be found at <http://www.cqc.state.ny.us/newsletter/news1.htm> (text or html version) and <http://www.cqc.state.ny.us/newsletter/news1.pdf> (pdf version).

The University of Buffalo's Department of Psychiatry finally has a new department chairman after a vacancy of more than a year: **Steven Dubovsky, MD**, formerly of the University of Colorado.



2003 -2004 NAMI Officers & Board

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The Challenger

Editor: Lynne Shuster

What's a Parent to Do?

For children and teenagers with mental illnesses, the greatest risk may be to do nothing, NAMI warned, as part of an ongoing national debate about treating children with psychiatric medications.

"Reaching children with appropriate treatment significantly improves their long-term prognosis. Conversely, the failure to provide treatment has tragic consequences," declares the report of a task force convened by the NAMI Policy Research Institute on "Children and Psychotropic Medications."

The report was released at a news conference at the National Press Club in Washington, D.C. You can obtain a copy of the report online at:

www.nami.org/kidsmeds.

"Mental illnesses are profound and lifethreatening illnesses. That's the reality before anyone even starts to talk about medications," said NAMI medical director Kenneth Duckworth, M.D., who presented the report at the National Press Club. "Life is uncertain. Risks are real and must be carefully weighed. But sometimes the worst risk lies in doing nothing."

Duckworth is a practicing child psychiatrist. He is also former Commissioner of Mental Health for Massachusetts and an assistant professor at Harvard Medical School.

The report comes at a time when the U.S. Surgeon General has warned that one in ten children or teenagers struggle with mental illnesses, but 80 percent never get the help they need. At the same time, the Food & Drug Administration (FDA) currently is reviewing the safety and effectiveness of using some psychiatric medicines with children. Questions also have arisen in other contexts, such as the role of schools in helping to identify early warning signs of mental illness.

The NAMI report does not seek to judge competing clinical studies, but instead emphasizes principles of sound clinical practice and overarching policy concerns, which Duckworth said "go to the heart of what it means to practice medicine." They include the right of parental choice, the

nature of the physician-patient relationship, and rights of access to effective treatments. The NPRI task force report recommendations include:

1. The National Institute of Mental Health (NIMH) must make children a priority and increase investment in scientific research focused both on the early onset of mental illnesses and long-term studies of the use of psychotropic medications in children.

2. One size does not fit all in treating mental illnesses. Individual treatment decisions must be based on the best information available as part of an evidence-based intervention (EBI) system. That includes full disclosure or "transparency" of existing clinical research studies.

3. Broad education is needed about early warning signs of mental illness in children. Parents must be supported by physicians and other child-serving professionals in making decisions on the use of psychotropic medications through informed consent, based on a careful weighing of risks and anticipated benefits. Use by children must be closely monitored and frequently evaluated.

4. Policymakers-whether in Congress or local school boards-should be guided by the medical principle of "First, do no harm." They should not interfere with rights of access to treatment or communication between parents, physicians, schools, and other potential support partners. Sound scientific research and testimony from well-qualified medical and mental health professionals and families must guide legislative or regulatory actions.

"Education, information, and communication are essential," Duckworth said. "So is pushing forward with scientific research. That is the foundation on which parents and doctors must make their decisions."

Please consider sharing this report with families, policymakers, providers, child-serving professionals, school professionals and other stakeholders interested in children's mental health.

Risperdal Consta Reimbursement

Medicare — Medicare reimburses for Risperdal Consta in physician offices, hospital outpatient departments and community Mental Health Centers under Part B of Medicare as a physician service. Clinics can bill for the drug and the administration.

Medicaid — Medicaid covers Risperdal Consta as a medical benefit and reimburses 100% for the cost of the drug in a physician office. (i.e. - private practicing psychiatrist). In CMHC's, Risperdal Consta is covered as part of the clinic rate established for that clinic (which is insufficient to cover the cost of the drug).

VA — Risperdal Consta is on the National VA formulary and available at VA Hospitals and outpatient clinics.

NYS Dept of Corrections — Risperdal is available on the NYS D.O.C. drug formulary.

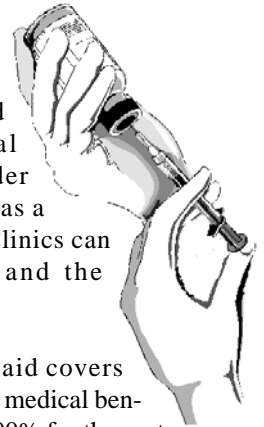
Independent Health — Covers Risperdal Consta as a pharmacy benefit with prior authorization. Medication is shipped to clinics via a specialty pharmacy distributor.

Blue Cross/Blue Shield — Risperdal Consta is reimbursed in physician offices, hospital outpatient departments and CMHC's as a medical benefit.

Univera — Risperdal Consta is reimbursed in physician offices, hospital outpatient departments and CMHC's as a medical benefit.

Indigent Patient without insurance coverage — Patient may be eligible for Janssen's Patient Assistance Program.

Patients and/or their providers can call: 1-800-Janssen for an application. Medication is provided to clinics free of charge for the patient.



Hearing Voices That Are Distressing: Self-Help Resources and Strategies

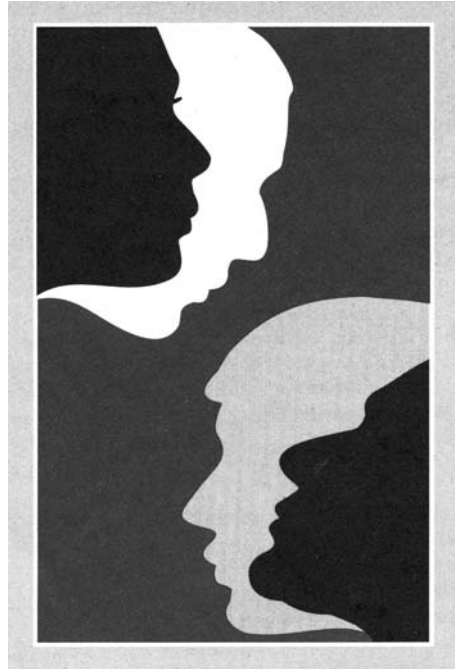
I have been a voice hearer since childhood but it was not until my adolescence that I was hospitalized for hearing voices that were distressing. For many years I felt isolated and stigmatized for carrying a label of mental illness and for hearing voices that continued to be distressing for me. Psychiatric drugs did not make my voices "go away" although there were times when I was so drugged I didn't care about anything, including what the voices had to say.

Therapists showed little interest in my voice hearing experiences. In fact, during the seventeen years that I was labeled and treated for schizophrenia, my therapists called my voice hearing experiences "auditory hallucinations." They seemed to view my voice hearing experience as nothing but the random fluctuation of neurotransmitters in my brain. In essence they viewed my "auditory hallucinations" as evidence of some sort of "neurotransmitter meltdown."

This attitude of ignoring voice hearers' experience is quite prevalent in the helping professions. For instance, when I consult to programs that provide services to people who hear voices that are distressing, I find it remarkable that staff know so little about the individual's experience. For example, I recently consulted with staff that work in a residential program with a man who hears distressing voices for approximately 80% of his waking hours. This man has been hearing distressing voices for more than ten years. Yet if you look at his record all it says is: "Has auditory hallucinations that sometimes command him to hurt himself."

In ten years of treatment no one has explored the voice hearing experience with this individual. No staff person has thought to inquire if the voices are male or female. Do they speak English? Are there helpful voices as well as distressing voices? How do you understand the existence of these voices? Are there one or many voices? When do the voices come and when don't they come? Do you have any personal power in relation to the voices - i.e., can you communicate with them, can you reason or bargain with them, can you turn your attention away from them and get involved with another activity, can you tell them you will talk with them later in the evening, etc.

Indeed, hearing voices seems to be stigmatized not only in the wider Western culture, but also within the mental health community as well. It seems that as a general rule, most mental health staff feel it is taboo to inquire into the voice hearing experience of the people they work with. Of course such stigma and taboo only serve to further isolate those of us who hear voices that are distressing.



The good news is that voice hearers themselves have begun to organize and speak out about the voice hearing experience. In the Netherlands and in England the Hearing Voices Network is being organized. The Hearing Voices Network is a member run organization that provides information, support groups, reports on relevant research, newsletters and conferences for people who hear voices. If you would like to contact the Hearing Voices Network and receive their "Information Pack" or to subscribe to their newsletter, write to: Hearing Voices Network, c/o Creative Support, Fourways House, 16 Tariff Street, Manchester, England, M1 2EP (telephone) 061-228-3896.

There are also two relatively new books that I highly recommend. The first book is called *Accepting Voices*, by Marius Romme and Sandra Escher (published by MIND PUBLICATIONS, London, England,

1993). This book is published in England and is not available yet in the United States. If you would like to order the book from England, write to the Hearing Voices Network at the above address. With postage charges, the book costs about \$30 U.S. dollars. Another excellent book is called *Hearing Voices: A Self Help Guide and Reference Book*, by John Watkins. This book is filled with lots of suggestions for coping with or eliminating voices. It can be ordered for \$9.50 U.S. dollars plus \$2 shipping and handling from Richmond Fellowship of Victoria, PO. Box 130, Brunswick West, Victoria, Australia 3055, (telephone) 03388-0466 or (fax) 03-380-4042.

Through these resources and networks voice hearers are beginning to let the world know that not all experiences of hearing voices are pathological or indicative of mental illness. Many people in Western Judeo/Christian culture have heard voices, including St. Paul, Joan of Arc, St. Francis, Socrates, William Blake, George Fox (founder of the Quakers), the classical music composer Robert Schumann and the psychiatrist Carl Jung. Hearing voices does not automatically mean you are "sick."

However, there are clearly voice hearing experiences that can be very distressing and can disrupt our lives and ability to work, make friends, reach our personal goals, etc. Voice hearers are beginning to learn from each other how to creatively cope with and/or eliminate distressing voices. We are learning that we do not have to be victims of our distressing voices. Some self help strategies include these: Don't isolate. Find people you can talk with about your voice hearing experience. Perhaps start a Hearing Voices Network in your area!

Some research suggests that if you put a rubber band around your wrist and snap it each time the distressing voices start, they will decrease in intensity and/or frequency. Some people have found it particularly helpful to use "I statements." For instance, if a voice begins to tell me I am a whore, worthless, no good, etc. I can say out loud, "Right now I feel worthless, I feel like I am

Continued on page 7

not good, I feel I am a whore," etc. This is very different from saying "the voices say I'm no good, a whore, worthless," etc. In this strategy I say what I am hearing and own it as my thought and when I do this the voices don't have to keep reminding me of it and they quiet down.

Keep a record. Some people have found it helpful to keep a record of the time, place, day and what they were doing just before the voices start up. By keeping a record for a few weeks you may begin to see a pattern. For instance you may begin to notice that your voices start up after visits to your family, after being in crowds, just before work, only when you use alcohol, etc. Once you notice a pattern, you can avoid those situations and thereby eliminate the voices related to those situations.

Try some music. Research has shown that for some people using a Walkman and listening to your favorite music can help diminish the intensity of voices. Interestingly, it's not that loud volume "drowns out the voices." Rather, what seems important is that your attention is focused on music you like. Thus, if you really like Metallica but only have a Brahms concerto to play on your walkman, no matter how loud you listen to Brahms it probably won't diminish your voices. So make sure you are listening to music that engages your attention and that you really like!

Don't forget that physical factors can affect the voice hearing experience. For instance, some people find that they hear voices that are particularly distressing when they have a fever or when they are premenstrual. Others find voice hearing gets worse after using alcohol, street drugs or over-the-counter drugs such as caffeine, sugar, antihistamines (cold medicines that cause drowsiness, such as Contact, Drixoral), etc. Knowing your body's reaction to fever, PMS, over-the-counter drugs, street drugs and other physical conditions can help you both predict when voices may be most distressing and help you eliminate these factors or at least be able to predict the length of time you will feel acutely distressed. For instance you could say "Each time I drink alcohol my voices get worse, so I will stop drinking alcohol" or you might say "Each time I am pre-menstrual my voices get worse so I know this will only last for several days and I will arrange for extra support from my friends each month during this time."

*Patricia Deegan, Ph.D.
Mental Health World
Summer 2004*

Research Reveals Biology of Harmful Stress

Scientists studying caregivers say the effects of chronic stress may last for years.

Taking care of a loved one can be deeply rewarding and has important benefits to society. But it can also place enormous stress on the caregiver, who is usually a woman. Scientists have recently begun to recognize some health risks associated with caregiving. Compared with non-caregivers, caregiving spouses have more depression, hypertension, infectious illness, and heart disease. They're also at greater risk for early death. Now researchers have located an immune system pathway that links caregiver stress to serious health problems. This mechanism apparently remains active even years after the stress is gone. The new findings contribute to our understanding of how stress can make you sick and why stress reduction may be a lifesaver.

Immune system consequences

As part of a long-term study examining stress and health in older caregivers, Ohio State University scientists followed 119 women and men who care for spouses with dementia, along with a similar number of age-matched non-caregivers. The subjects gave regular blood samples and answered questions about stress, depression, and loneliness.

The findings, published in the July 2, 2003, Proceedings of the National Academy of Sciences Online, focus on interleukin-6 (IL6), a compound that circulates in the blood and helps regulate the immune system. Excess IL-6 plays a role in muscle atrophy and several diseases of aging. It promotes the production of C-reactive protein (CRP), a risk factor for cardiovascular disease. And both IL-6 and CRP are implicated in type 2 diabetes, osteoporosis, and arthritis.

On average, the caregivers in the study had four times as much IL-6 in their blood as the non-caregivers - an effect that continued for several years after the spouse had



died. According to the researchers, this suggests that chronic stress may have a lasting impact on the immune system.

These results could have broader implications, the researchers say, if other forms of chronic stress cause similar increases in IL-6. The problem may be compounded by some of the unhealthy habits people develop in response to stress, such as smoking, overeating, sleeping too little, and not exercising. These, too, are linked to higher IL-6 levels.

What now?

Whether you're a caregiver or not, it may be time to take a fresh look at your own situation and, if necessary, commit yourself to finding some stress relief:

- If you're caring for someone with dementia, learn how to manage some of his or her difficult behaviors, such as refusing to cooperate or wandering. Your primary care provider may have some advice or can direct you to a training program.
- Get some help with caregiving. Call on friends and relatives. Investigate respite care (a substitute caregiver) so you can get a break.
- Consider psychotherapy or a support group to help you develop coping strategies and problem-solving skills.
- Take care of yourself. Eat a balanced diet, avoid fatty foods, and take a multivitamin. Get enough sleep, limit your alcohol use, and try to fit in some daily exercise.
- Try a mind-body approach to stress management. Activities such as deep breathing, meditation, visualization, yoga, and tai chi can help reduce blood pressure, heart rate, and muscle tension.

*Harvard Woman's Health Watch
Vol 11, No. 1
September 2003*

Electroconvulsive Therapy(ECT)

"What you need to know about Electroconvulsive Therapy"

What is Electroconvulsive Therapy?

Electroconvulsive therapy(ECT) is a modern medical treatment for certain illnesses that have mental or emotional symptoms. In this treatment, the patient goes to sleep under anesthesia, receives muscle relaxants and oxygen, and then receives a brief electrical stimulation to the scalp. The resultant nerve-cell activity releases chemicals in the brain and helps to restore normal functioning. ECT resembles cardioversion, a common medical procedure in which the heart is stimulated electrically to restore its normal functioning, but ECT uses a much smaller amount of electricity.

ECT has been used for over 50 years. The American Psychiatric Association concluded in 1978 that ECT was both safe and effective for cases of severe depression and several other severe mental illnesses. More recently, a blue ribbon panel convened in 1985 by the U.S. Government's National Institutes of Mental Health found that ECT was "demonstrably effective for a narrow range of severe psychiatric disorders", including depression, mania and schizophrenia.

Medication helps many people suffering from the aforementioned psychiatric disorders but for over 30,1000 U.S. patients each year, ECT is the most effective treatment. Some patients do not respond to medications, others cannot tolerate the side effects, and still others - those whose illness has made them seriously suicidal, for example - urgently require the reliable symptom relief that ECT can provide.

How is ECT Given?

ECT is given by a treatment team of doctors, nurses, and nursing assistants, often with an anesthesia specialist. With the patient reclining, a sleeping medication is injected in a vein and the patient rapidly falls asleep. A muscle relaxing medication is then injected, while the patient breathes pure oxygen. When the muscles are relaxed, a brief electrical charge is applied to the scalp, stimulating the brain into rhythmical activity that lasts about one minute and is accompanied by release of chemicals from nerves in the brain. Mild contractions of the muscles occur during this "convulsion". When it is over, the patient is taken to the recovery area and observed by trained staff until he/she awakens, usually in about 20 minutes.

ECT is usually given two or three times a week, typically Monday, Wednesday and Friday mornings, for a total of 6 to 12 treatments. A few patients may require more than 12 treatments for maximum benefit.

Is ECT Curative?

ECT is an exceptionally effective medical treatment, helping 90% of patients who take it. Most patients remain well for many months afterwards. The tendency to relapse after a favorable treatment outcome can often be countered by medication taken for about half a year after ECT. Permanent cures for psychiatric illnesses are rare, however, regardless of the treatment given.

How Safe is ECT?

ECT is a very safe medical treatment. A recent study in California found about one death per 50,000 ECT treatments, a risk far below the risk of child birth. Another study observed the death from heart attacks and suicide were less frequent among depressed patients who had received ECT than among those who had not. With modern anesthesia, fractures and oxygen deprivation virtually never occur, and many patients with high blood pressure or heart conditions can safely be treated.

The dramatization of ECT in movies like "One Flew Over the Cuckoo's Nest" bears no resemblance to modern ECT, which is neither painful nor a punishment. Most patients surveyed after ECT said it was no worse than going to the dentist, and many found ECT less stressful.

How Does ECT Work?

Although it is necessary for the brain cells to interact with each other chemically and electrically for ECT to work, exactly how this interaction is therapeutic needs further investigation. We believe that patients with melancholia have a severe biochemical disorder of the nervous system that ECT corrects. A number of rigorously designed research projects are under way to study this question.

What are the Main Side-Effects of ECT?

On awakening from ECT, it is customary for patients to experience some confusion, which generally clears within an hour. Memory for recent events, addresses, and telephone num-

bers may not be as good. In most patients, the memory disturbance goes away within a few days or weeks, but it can continue in a mild form for a period of months. Many patients will find that their memories are somewhat hazy for the time they were ill; the same period is frequently experienced by depressed patients who do not receive ECT. Memory disturbances are not needed for ECT to work and doctors use special techniques (such as brief pulse ECT) to minimize or avoid any effects on memory.

Can ECT Cause Brain Damage?

The available evidence speaks against this possibility. Patients receiving ECT show no evidence of brain enzymes that are released into the bloodstream when brain damage occurs, such as after a stroke. Animal studies have shown that oxygen administration is essential during ECT, as it is in surgery. Even after experimental seizures lasting for hours, with plentiful oxygen, there is no evidence of brain damage. This is why ECT is always given under oxygen and with muscle relaxants to aid oxygen delivery.

Does ECT cause Permanent Memory Loss?

Not in most people. Most importantly, ECT does not interfere with the ability to learn, and many studies have shown better learning after ECT than before it, probably because of improved concentration from relief of depression. A few patients, however, still have not regained some specific personal memories when tested six months after receiving a form of treatment called bilateral ECT. Generally, these memories are for events in the months immediately preceding. No long term or persistent effects of ECT on intellectual abilities or memory problems in patients with psychiatric illness result more often from medication and incompletely treated illness.

Why Does ECT's Public Image Suffer?

Just as with other medical treatments, ECT was used excessively in the past, mostly in large understaffed mental hospitals in the 1940's. The drama of mental illness has also been exploited by fictional movies such as "The Snake Pit" that indicates stark and more exaggerated portrayals of ECT to emphasize a story. More recently, quasi-religious groups have received media attention for unsubstantiated claims that all medical approaches to psychiatric illness are undesirable.

Stop Putting Sick Children in Jail

Congressional Investigative Report Released

NAMI (National Alliance for the Mentally 111) condemned state and local governments that warehouse children and adolescents with mental illnesses in the juvenile justice system - simply because adequate treatment and services in their communities are not available.

"We are spending money in all the wrong places," declared NAMI Maine executive director Carol Carothers, testifying on behalf of NAMI before a hearing of the U.S. Senate Governmental Affairs Committee on a Congressional investigative report on the scandal. The full text of her testimony is available online at www.nami.org/kidsjails.

The widespread warehousing of children with mental illnesses in juvenile justice facilities was revealed in the investigative report jointly released by the Senate Governmental Affairs Committee and the House Committee on Government Reform. The report, entitled "Incarceration of Youth who are Waiting for Community Mental Health Services in the United States", reveals that youth with mental illnesses are commonly held in juvenile detention centers without any charges against them, while waiting for treatment.

Senator Susan Collins, (R - Maine), Chair of the Senate Governmental Affairs Committee, called these inappropriate detentions "a regrettable symptom of a much larger problem, which is the lack of available, affordable, and appropriate mental health services and support systems for children with mental illness and their families ...

When a child has a serious health problem like diabetes or a heart condition, the family turns to their doctor. When the family includes a child with a serious mental illness, it is often forced to go to the child welfare or juvenile justice system to secure treatment. Neither of these systems is equipped to care for a child with a serious



mental illness, but in far too many cases, there is nowhere else for the family to turn."

The report was prepared jointly for Senator Collins and Representative Henry Waxman (D - California), ranking minority member of the House Committee on Government Reform. Representative Waxman called for an immediate end to the shameful practices revealed in the report. "It is shocking that so many youth are jailed unnecessarily because they cannot obtain community mental health services. This is a crisis that demands the attention of Congress."

In Maine, Carothers noted, 10 year old children may be housed with 20 year olds, where they are vulnerable to physical or sexual assaults. Keeping children in the community, however, leads to better outcomes and saves taxpayer dollars: \$30,000 to provide intensive in-house services for a family for one year, compared to \$80,000 to lock a child in a detention center.

The Congressional investigative report documents "a national crisis", Carothers

said, resulting in part from reduction or elimination of mental health services as states struggle to balance budgets. However, money cut from such services is not saved. "Instead, it will be shifted to corrections budgets, a waste of the taxpayer's money."

Carothers is one of 10 persons nationwide recently honored with a \$120,000 award from the Robert Wood Johnson Community Health Leadership Program, for efforts to reform Maine's mental health and criminal justice systems. In her testimony, she also referred to a three-part investigative series, "Castaway Children," published by the Maine's Portland Press Herald in 2002.

Carothers called on Congress to enact the:

■ Keeping Families Together Act (S.1704/H.R.3243) to provide grants to states to develop more comprehensive, coordinated community-based services for children.

■ Family Opportunity Act to allow families with children with serious disabilities to buy into Medicaid for essential services.

■ Mental Health Equitable Treatment Act to prohibit discriminatory limits on mental health benefits in private insurance coverage.

■ The Mentally 111 Offender Treatment and Crime Reduction Act (S. 1194/ H.R. 2387) to support jail diversion programs for treatment.

A copy of the report can be found at: www.nami.org/kidsjailsreport

A copy of NAMI's press release about the report can be found at: www.nami.org, click on the "Top Story" and there will be a link from there to the press release.

Coping Tips for Family Members Who Have a Relative with a Mental Illness

1. You cannot cure a mental illness for a family member.
2. Despite your efforts, symptoms may get worse, or may improve.
3. If you feel much resentment, you are giving too much.
4. It is as hard for the individual to accept the illness as it is for other family members.
5. Acceptance of the disorder by all concerned may be helpful, but not necessary.
6. A delusion will not go away by reasoning and therefore needs no discussion.
7. Symptoms may change over time while the underlying disorder remains.
8. You may learn something about yourself as you learn about a family member's mental disorder.
9. Separate the person from the disorder. Love the person, even if you hate the disorder.
10. Separate medication side effects from the disorder/person.
11. It is not okay for you to be neglected. You have needs & wants too.
12. Your chances of getting mental illness as a sibling or adult child of someone with mental illness are 10-14% . If you are older than 30, they are negligible (very small) for schizophrenia.
13. Your children's chances are approximately 2-4%, compared to the general population of 1%.
14. The illness of a family member is nothing to be ashamed of. Reality is that you may encounter discrimination from an apprehensive (fearful) public.
15. No one is to blame.



16. Don't forget your sense of humor.
17. It may be necessary to revise your expectation.
18. Success for each individual may be different.
19. Acknowledge the remarkable courage your family member may show in dealing with a mental illness.
20. Your family member is entitled to his/her own life journey, as you are.
21. Grief issues for siblings are about what you had and lost. For adult children, the issues are about what you never had.
22. After denial, sadness, and anger, comes acceptance. The addition of understanding yields compassion.

*Adapted from Rex Dickens
NAMI Sibling and Adult Children Network*

10 Best Mental Health Hospitals in the US

Massachusetts General Hospital, *Boston*
 New York Presbyterian Hospital
 McLean Hospital, *Belmont, MA*
 C.F. Menninger Memorial Hospital, *Topeka, KN*
 Johns Hopkins Hospital, *Baltimore*
 UCLA Neuropsychiatric Hospital, *Los Angeles*
 Yale-New Haven Hospital, *New Haven, CN*
 Mayo Clinic, *Rochester, MN*
 Duke University Medical Center, *Durham, NC*
 University of Pittsburgh Medical Center

In Brief...

Effects of Long-Term Antidepressant Treatment

J.H. Kocsis and others report positive results of long-term antidepressant treatment in a study of 161 patients. Following 12 weeks of treatment study participants were divided into two groups, with half receiving placebo and half receiving continuing medication for sixteen weeks. "The study found patients on placebo grew worse compared to those on continuing medication. The researchers report that by the end of the 18 weeks of treatment, patients achieved "normalization" in 58 to 64 percent of the time.

Archives of General Psychiatry
2002; 59: 723-728.

E-EPA Acid Evaluated as Add-on Treatment in Schizophrenia

A small, randomized, double-blind placebo-controlled study has found positive clinical effects with the addition of ethyl-eicosapentaenoic acid (E-EPA) as a supplemental treatment in schizophrenia. Forty patients who had received at least six months of fixed-dose antipsychotic therapy were divided into two groups. One group received placebo for twelve weeks, the other 3g a day (three 500 mg capsules twice a day) in addition to their existing treatment. The E-EPA group showed "significantly greater reductions" in symptoms and also a "significantly greater reduction in tardive dyskinesia." The researchers note, "If E-EPA's efficacy in psychosis and tardive dyskinesia is confirmed, it is likely to lead to revision of our understanding of the pathophysiology and treatment of these disorders."

R. Emsley, et. al.
American Journal of Psychiatry
2002; 159: 1596-1598

Meds and Diabetes

All newer generation, atypical antipsychotic medications must now carry a "black box" warning about the risk of developing diabetes associated with use of these medications. A number of experts recommend a fasting glucose tolerance test before patients start taking these drugs, and periodic testing for as long as the patient continues to take such medications.

Early Intervention May Prevent Psychosis in High-Risk Patients

Oct. 21, 2002 - Treating those at ultra-high risk for early transition to psychosis with pharmacotherapy and psychotherapy postpones or prevents progression, according to the results of a small controlled trial presented in the October issue of the Archives of General Psychiatry.

"Most disability produced by psychotic illnesses, especially schizophrenia, develops during the prepsychotic period, creating a case for intervention during this period," write Patrick D. McGorry, PhD, and colleagues from the University of Melbourne in Australia. "However, only recently has it been possible to engage people in treatment during this phase."

This randomized trial compared two interventions in 59 patients with subthreshold symptoms who were at incipient risk of progression to first-episode psychosis, termed "ultra-high risk" to emphasize their enhanced risk relative to subjects in genetic high-risk studies. During the first six months of treatment, subjects received needs-based intervention or specific preventive intervention with low-dose risperidone (mean dosage, 1.3 mg/day) and cognitive behavior therapy. During the next six months, all patients were offered ongoing needs-based intervention.

After study treatment, 10 of 28 subjects in the needs-based group progressed to first-episode psychosis, as did three of 31 in the preventive group (P=.03). Six months later, another three subjects in the preventive group developed psychosis. With intention-to-treat analysis, the difference was no longer significant (P=24). However, for patients in the preventive group who adhered to risperidone therapy, protection against progression extended for six months after discontinuation of risperidone.

"More specific pharmacotherapy and psychotherapy reduces the risk of early transition to psychosis in young people at ultra-high risk, although their relative contributions could not be determined," the authors write. "This represents at least delay in onset (prevalence reduction), and possibly some reduction in incidence."

Laurie Barclay, MD
Medscape

Study Examines Use of Acupuncture to Aid Those with Bipolar Disorders

Dr. Tricia Suppes has long been concerned about the 1.9 million Americans with bipolar disorder, also known as manic-depressive illness. That's why she's investigating a new use for an old therapy: acupuncture.

"Bipolar disorder is a common, severe and persistent mental illness that - without effective treatment - disrupts the lives of patients and their families," said Suppes, associate professor of psychiatry at UT Southwestern Medical Center at Dallas. "If the treatment is inadequate and the patient does not respond well to currently available drugs, the disease may lead to loss of jobs, marriages and even lives. The need for new treatments is critical."

Suppes is currently enrolling patients 18 to 65 years old who are in the depressed stage of bipolar disorder. In this disorder, patients cycle between depression and elation, extreme irritation or anger.

The study, funded by the National Institute of Mental Health, is the first to evaluate acupuncture as an adjunct to medication for treatment of bipolar illness although an earlier published study at the University of Arizona College of Medicine reported positive results on the use of acupuncture as a treatment for major, or unipolar, depression. Suppes wants to learn whether supplementing bipolar patients' medications with acupuncture will allow some to reduce their medication.

Current psychotropic medications for bipolar disorder do not work well for many patients. Suppes said some must take a combination of medications daily that can cause significant side effects and can be costly for patients without insurance. That often causes patients to discontinue their medication, she said.


The study will involve 30 male and female patients randomly divided into two groups. Some will receive acupuncture directed toward treating depressive symptoms. Others will receive nonspecific acupuncture, which treats certain physical complaints. Patients, who will continue on their regular medications during the trial, will not know which type of acupuncture they

are receiving. All will be treated free for eight weeks. The patients receiving non-specific acupuncture will be offered acupuncture specifically intended for depression at the conclusion of the trial.

For further information about the study, call the Bipolar Disorder Clinic and Research Program at 214-648-7474. University of Texas Southwestern.

Zyprexa Dementia Warning

Eli Lilly has sent a letter to doctors warning that Zyprexa significantly increases the risk of death and stroke in elderly patients with dementia. Last year, Johnson & Johnson issued a similar warning concerning Risperdal. According to Eli Lilly, 3.5 percent of elderly patients with dementia taking Zyprexa in trials died of all causes vs 1.5 percent among those taking placebos. The drug has been used off-label to treat dementia.



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Antidepressants Protect Brain from Depression-related Shrinkage

Previous research has found that the hippocampus—a region of the brain crucial to learning and memory—is smaller in people who suffer from recurrent bouts of depression. A newly released study of women with histories of clinical depression suggests that antidepressants may help counter this effect, potentially alleviating not only depression but also some of the cognitive problems that may accompany it.

The hippocampus is important for processing newly acquired memories of facts and events. It lets you remember, for example, the name of the person you just met, or that Australia is the only country that's also a continent. This form of memory can suffer whenever there is any type of hippocampal damage. Recent research in animals indicates that antidepressants help stimulate cell growth in this part of the brain and that this accounts for their ability to reduce depressive symptoms. According to researchers at Washington University School of Medicine in St. Louis, these drugs may have the same effect in humans.

Although researchers didn't look at the effects of specific antidepressants on the hippocampus, it appears that any one of them protected the brain better than no treatment. The researchers suggest that if you're depressed, it's best not to put off seeking help. In this study, damage to the hippocampus got worse with each depressive episode.

Sparkling new brain cell growth

According to a study published in the August 8, 2003, issue of *Science*, antidepressants work by stimulating new brain cell growth, a process known as neurogenesis - at least that's the case in mice. However, neurogenesis takes time, which may explain why antidepressants don't start working until several weeks after treatment has begun.

Scientists at Columbia University and other schools treated mice with fluoxetine (Prozac). After 28 days of treatment, the mice were less anxious about fetching their food, an indication that the drugs

were working. This effect was not apparent in mice treated for only five days.

The researchers also found that when they experimentally blocked new brain cell growth, the antidepressants had no effect on behavior. More research is needed to clarify the relationship between neurogenesis and depression or stress, both of which have been linked to hippocampal shrinkage.

Harvard Woman's Health Watch
October, 2003

Common Drug List Plan Alarms Mental Health Groups

A proposed plan by several states to pool their purchasing power to negotiate lower prices from pharmaceutical companies for medications in Medicaid may jeopardize consumer health if they restrict access to medications, mental health groups are warning.

The National Alliance for the Mentally III (NAMI) and the National Mental Health Association (NMHA) are jointly urging policy makers not to put in any plan that could restrict patient access to better antipsychotic medications.

While acknowledging the fiscal crisis some states are facing, the proposed pooling plan is "penny-wise but pound-foolish," NAMI said in a March news release. NAMI and the NMHA want policy makers wrestling with scarce budget resources in 2003 to find solutions that do not come at the expense of people with mental illnesses.

Under a new proposal, Michigan, Minnesota, Vermont, Wisconsin and possibly more states plan to set up a common preferred drug list based on cost rather than health and safety, NAMI says. The association says the drug list could restrict patients' and physicians' choices of antipsychotic medications, which could increase costs through increased hospitalizations and emergency care for people with mental illnesses.

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