



The Newsletter
of the Philadelphia Affiliate of the
National Obsessive-Compulsive Foundation

The G.O.A.L. Post

to familiarize the public with OCD
and OCD spectrum disorders, to
educate and to encourage those
affected, and to promote
understanding among their families,
colleagues, and friends

Living Obsessive-compulsives Another Lifestyle

Volume 10, Issue 3

Fall 2008

A TESTAMENT TO TRANSFORMATION

For Megan
by Terri Adamczyk, boarder

The moving day we've planned does not arrive; mother finally sees what we have seen, that things are not yet fit to be moved, all the papers and the books my mother has collected have not been boxed or thrown away. The furniture and floor are covered with these things and others I've not looked close enough to recognize. I ask if I can help her clean or bag or box a place or two, and she says yes in just this special way that means, not really. I ask her if she thinks she'll finish in time, and as if she lived in another world where all this stuff surrounding her does not exist, she serenely says, "Yes, of course." 17 years of hoarding to root through and box up but absolutely not to throw away. There's so much here around us, folders from 1989, birthday candles left behind in what once was the living room and waiting to be reused. All these things and more testify that our tenancy will never end or not by the thirty-first. It all reminds me of ivy surrounding a house, but inside not outside, and just like the ivy there's no end to what covers the floors and the furniture, all of which passed human occupancy years ago. I fear we will never be through because my mother will never let go—not of any one thing—whatever is part of her piles she plans to bring with us. Whether it's strewn on the floor or the couch, all of it is something she gives her heart to in earnest, as if it were touched by a saint and holy, not to be thrown away; even to throw away the broken typewriter the children once liked playing with is to break her heart into a million pieces. She cannot believe the memory will stay with her always, that she doesn't need the now useless object for it to exist in her mind new and shiny and played with by her now grown girls. In her mind if she throws the toy away the little girls she loved will disappear. And the papers—all the papers—are important, and many things—other things—must be kept because some day they may be needed, although whatever should happen to become necessary won't be found because it's hidden beneath so many things with no place to be, hidden in piles with no sense nor form, and no function, and this is not in one place but everywhere, and yet my mother has no eyes for seeing confusion. We'll never be able to discard all the trash and find what we want. Worse, it looks like we'll pack all of the trash and start over just as we were, an awful enough outcome, but more horrible still the work will be endless, never to be finished by the thirty-first whether or not I take

over with trash bags and boxes and scoop up pile after pile of printed word that has long ago encroached on even her bed because each paper is filled on each page with stories and a story is meant to be treasured even through in the heaps of papers you'll never find that story you want. I start trashing the papers and magazines and church bulletins. Passively my mother lets me while she endlessly cleans the kitchen, washing every bottle in the pantry and each bauble hanging in the window. I conquer her room and she continues to dither this way and that in the kitchen. I move on to the living room, my heart in my throat when I look without bleary, half-closed eyes at the truth of what lies ahead. More trash bags are needed and more fortitude than I think I possess, and I know we will not reach the end by the thirty-first. The movers are canceled to be rescheduled later, hopefully. But my mother, unfazed, keeps pacing the kitchen as if it were an architectural site where each piece must be plotted and noted and dusted. Everything I do seems too much until I see the attic and then I feel like one who observes Mt. Everest from its base and I cannot imagine the precarious mount to its top though it happens, so this too can happen and after my days in the dust and the heat this too has changed into heaps of old trash. I've conquered it, eave to eave, till eventually the trash is transferred to the curb, the desirables taken to their new home. Mother no doubt has finished the kitchen but it's all two months late, for which we will pay and sadly mother prefers not to open her boxes and bags, knowing her most cherished objects are hoarded away where no one like me can savagely throw them away. But nor are they free for her use.



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The Philadelphia
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Foundation



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THE DANGER OF HOARDING

*by Joyce Cohen,
Special for USA TODAY
February 18, 2004*

For 25 years, a difficult-neighbor problem plagued Curtis and Elaine Colvin of Seattle. The neighbor's home and lawn resembled a junkyard.

Finally, last spring, the elderly man was taken out of state by relatives. Konstantinos Apostolou bought the house—and sent in five men to clear the floor-to-ceiling junk.

"It was the most disgusting thing I've ever seen in my life," says his son, George Apostolou.

There was nowhere to walk, except for a narrow "goat path" connecting the rooms. The men hauled out seven dumpsters' worth of clothes, books, magazines, spoiled food, firewood, car parts, tires, bank statements, and 50-year-old tax records.

"I feel bad for the guy," says Apostolou. "I'm sure he was ill."

Just how ill is still little understood. The man was a classic hoarder—a condition usually considered freakish and laughable, or dismissed with cutesy terms like "pack rat" and "junkaholic." Only now is hoarding garnering serious attention.

Within the past six years, about 10 municipalities have formed task forces so that public services can collaborate in cleaning up the property and helping the hoarder. And researchers are studying how hoarding differs from seemingly related conditions. Hoarding is currently considered one of the symptoms of obsessive-compulsive disorder (OCD).

Hoarders don't just save stuff, but constantly acquire new stuff—to such a remarkable degree that it interferes with functioning and safety.

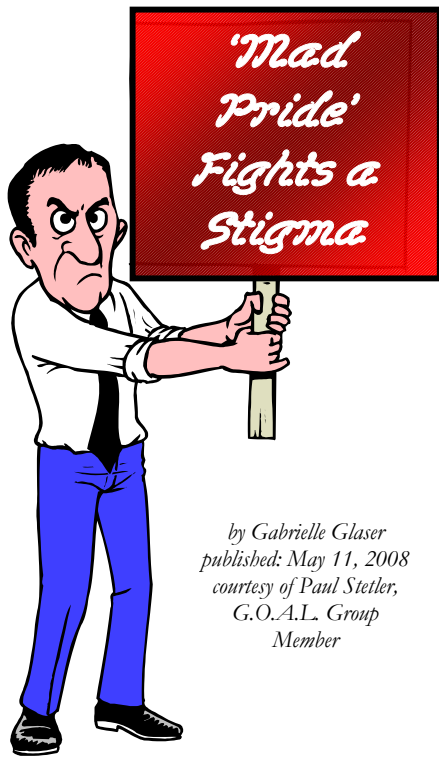
It's unclear how widespread hoarding is, since the problem often surfaces only after a neighbor's complaint or a medical emergency. Randy Frost, a psychology professor at Smith College in Northampton, Mass., estimates that 2% to 3% of the population has OCD, and up to a third of those exhibit hoarding behavior.

Real danger can lurk in homes overflowing with stuff. Floors buckle from the weight. People get buried under piles. Insects and rodents feast on rotting food. Combustibles ignite, endangering both occupants and firefighters.

Fairfax County, Va., formed one of the first task forces in 1998 after squatters settled in a house vacated by a hoarder, lit a fire in the fireplace, and died in the ensuing blaze.

Behavioral peculiarities among hoarders come as no surprise to researchers.

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by Gabrielle Glaser
published: May 11, 2008
courtesy of Paul Stetler,
G.O.A.L. Group
Member

In the YouTube video, Liz Spikol is smiling and animated, the light glinting off her large hoop earrings. Deadpan, she holds up a diaper. It is not, she explains, a hygienic item for a giantess, but rather a prop to illustrate how much control people lose when they undergo electroconvulsive therapy, or ECT, as she did 12 years ago.

In other videos and blog postings, Ms. Spikol, a 39-year-old writer in Philadelphia who has bipolar disorder, describes a period of psychosis so severe she jumped out of her mother's car and ran away like a scared dog.

In lectures across the country, Elyn Saks, a law professor and associate dean at the University of Southern California, recounts the florid visions she has experienced during her lifelong battle with schizophrenia—dancing ashtrays, houses that spoke to her—and hospitalizations where she was strapped down with leather restraints and force-fed medications.

Like many Americans who have severe forms of mental illness such as schizophrenia and bipolar disorder, Ms. Saks and Ms. Spikol are speaking candidly and publicly about their demons. Their frank talk is part of a conversation about mental illness (or as some prefer to put it, "extreme mental states") that stretches from college campuses to community health centers, from YouTube to online forums.

"Until now, the acceptance of mental illness has pretty much stopped at depression," said Charles Barber, a lecturer in psychiatry at the Yale School of Medicine. "But a newer generation, fueled by the Internet and other sophisticated delivery systems, is saying, 'We deserve to be heard, too.'"

About 5.7 million Americans over 18 have bipolar disorder, which is classified as a mood disorder, according to the National Institute of Mental Health. Another 2.4 million have schizophrenia, which is considered a thought disorder. The small slice of this disparate population who have chosen to share their experiences with the public liken their efforts to those of the gay-rights and similar movements of a generation ago.

Just as gay-rights activists reclaimed the word queer as a badge of honor rather than a slur, these advocates proudly call themselves mad; they say their conditions do not preclude them from productive lives.

Mad pride events, organized by loosely connected groups in at least seven countries including Australia, South Africa and the United States, draw thousands of participants, said David W. Oaks, the director of MindFreedom International, a nonprofit group in Eugene, Ore., that tracks the events and says it has 10,000 members.

Recent mad pride activities include a Mad Pride Cabaret in Vancouver, British Columbia; a Mad Pride March in Accra, Ghana;

and a Bonkersfest in London that drew 3,000 participants. (A follow-up Bonkersfest is planned next month at the site of the original Bedlam asylum.)

Members of the mad pride movement do not always agree on their aims and intentions. For some, the objective is to continue the destigmatization of mental illness. A vocal, controversial wing rejects the need to treat mental afflictions with psychotropic drugs and seeks alternatives to the shifting, often inconsistent care offered by the medical establishment. Many members of the movement say they are publicly discussing their own struggles to help those with similar conditions and to inform the general public.

"It used to be you were labeled with your diagnosis and that was it; you were marginalized," said Molly Sprengelmeyer, an organizer for the Asheville Radical Mental Health Collective, a mad pride group in North Carolina. "If people found out, it was a death sentence, professionally and socially."

She added, "We are hoping to change all that by talking."

The confessional mood encouraged by memoirs and blogs, as well as the self-help advocacy movement in mental health, have deepened the understanding of bipolar disorder and schizophrenia. Books such as Kay Redfield Jamison's autobiography, *An Unquiet Mind: A Memoir of Moods and Madness*, have raised awareness of bipolar disorder, and movies like *Shine* and *A Beautiful Mind* have opened discussion on schizophrenia and related illnesses. In recent years, groups have started antistigma campaigns, and even the federal government embraces the message, with an ad campaign aimed at young adults to encourage them to support friends with mental illness.

Members of MindFreedom International, which Mr. Oaks founded in the 1980s, have protested drug companies and participated in hunger strikes to demand proof that drugs can manage chemical imbalances in the brain. Mr. Oaks, who was found to be schizophrenic and manic-depressive while an undergraduate at Harvard, says he maintains his mental health with exercise, diet, peer counseling, and wilderness trips—strategies that are well outside the mainstream thinking of psychiatrists and many patients.

Other support groups include the Mad Tea Party in Chicago and the Freedom Center in Northampton, Mass., which provides education, acupuncture, yoga, and peer discussions to about 100 participants.

The Icarus Project, a New York-based online forum and support network, says it attracts 5,000 unique visitors a month to its Web site, and it has inspired autonomous local chapters in Portland, Ore., St. Louis, and Richmond, Va. Participants write and distribute publications, stage community talks, trade strategies for staying well and often share duties like cooking or shopping.

The Icarus Project says its participants are "navigating the space between brilliance and madness." It began six years ago, after one of its founders, Sascha Altman DuBrul, now 33, wrote about his bipolar disorder in *The San Francisco Bay Guardian*, a weekly newspaper. Mr. DuBrul, who is known as Sascha Scatter, received an overwhelming response from readers who had experienced similar ordeals, but who felt they had no one to discuss them with.

"We wanted to create a new language that resonated with our actual experiences," Mr. DuBrul said in a telephone interview.

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ARE YOU CRAZY ENOUGH TO SUCCEED?

Obsessive and compulsive behaviors can make you—or break you

by *Jeremy Katz*
edited from **MEN'SHEALTH**
July, 13, 2008
courtesy of Paul Stetler, G.O.A.L. Group Member

I sit in the glass-walled nurses' station, waiting for my day to begin. A steady stream of people—all living with obsessive-compulsive disorder, or OCD—approach the half door and utter some variation of "I have to go to the bathroom." The attractive young woman on duty smiles and hands over a small quantity of toilet paper, a squirt of soap in a specimen cup, and a paper towel with a cheery "Here you are!" This is what grade school must have seemed like to George Orwell.

Pretty soon I have to go, too. How could I not?

I'm here to interview the doctor, not seek treatment from him, so I'm directed empty-handed to a staff bathroom in which I discover four separate soap dispensers, a forest of paper products, and two signs about washing my hands—one to remind me to do it, and the other to tell me how.

I'm at the Obsessive Compulsive Disorders Institute (OCDI), a residential treatment center in McLean Hospital—Harvard's psychiatric center—to see if my own OCD problem wasn't just my secret but maybe also the secret to my success. All my adult life, intrusive thoughts have alternately halted my progress and saved my ass, and I'd finally like to separate the bad from the good.

The medical director at the center, Michael Jenike, M.D., is both a maverick and a pioneer in the OCD community. He founded this facility, the first of its kind, to help sufferers of what he considers the most agonizing of psychiatric disorders.

"I had a 17-year-old who had kidney cancer that was going to kill him in 5 or 6 months. He also had a bad case of OCD. He said he'd rather get rid of his OCD and live only 6 months, than get rid of the cancer and live with the OCD. That's when it first hit me: This is some serious stuff."

The people seeking treatment at OCDI do not have the minstrel-show version of the disorder acted out by Tony Shalhoub in *Monk* or Jack Nicholson in *As Good as It Gets*. The institute's residents are seriously impaired. They have the kind of shattering anxiety that would make the rest of the OCD world—roughly 1 percent of all adults, 2.3 million of them in the United States alone—want to scrub their hands. The real numbers could be even higher, because OCD may be underdiagnosed and undertreated. Half of all OCD cases are serious—and that's the highest percentage among all anxiety disorders. On average, people flail about for 17 years and see three or four doctors before they find the right care.

That horror aside, OCD has become cool. Perhaps it fascinates us because it forces otherwise normal people to carry out insane acts—acts that they know are insane. It has great dramatic tension. We secretly enjoy the dissonance of a perfectly rational man becoming convinced that he is fatally contaminated and washing his hands with bleach and a scrub brush, only to repeat the whole routine 10 minutes later. Paging Lady Macbeth.

And anyway, who wouldn't want a condition David Beckham has, even if it is his signature brand of mental illness? The popularization of the disorder has led to a heap of confusion. Everyone I know is "obsessed" or "compulsive" about something.

And then there's the throwaway excuse of our times: "Oh, that's just my OCD."

This casual imprecision only adds to the confusion of talking about OCD. Sanjaya Saxena, M.D., an associate professor of psychiatry and behavioral sciences at the University of California at San Diego and the director of the school's OCD program, points out that "the meanings of 'compulsion' and 'obsession' as we speak of them in common parlance are not the same as the strict mental-health definitions." Obsessing about your work or your girlfriend doesn't mean you have OCD, and most people understand that "compulsively" keeping a neat desk or managing a stock portfolio is no big deal.

More to the point, those everyday fixations do not put you in danger of developing full-blown OCD. Even habits that are worrisome and possibly progressive, such as sex addiction, compulsive gambling, or overdrinking, fall within the spectrum of addictive behavior and not OCD.

Like our common, everyday infatuations, says Dr. Saxena, these habits persist "because they are rewarding in and of their own right." A true obsession, though, is "a recurrent, intrusive fear, impulse, or image that is distressing and anxiety-provoking," he says, while a compulsion is "a repetitive behavior done in response to an obsessional fear or worry and designed to prevent something bad from happening or to reduce distress."

If the behavior produces pleasure or a reward—even a strange or unhealthy reward—it's not a real obsession or compulsion, and it won't develop into one. Gerald Nestadt, M.D., a professor of psychiatry at Johns Hopkins, puts it this way: "The alcoholic may say, 'I shouldn't drink, but I love to,' whereas the person with a contamination obsession would say, 'I don't want to wash my hands, and I wish I could stop.' The reason the addictive person wants to stop is only because of the consequences, not the unwanted urge."

'The core of all anxiety is uncertainty'

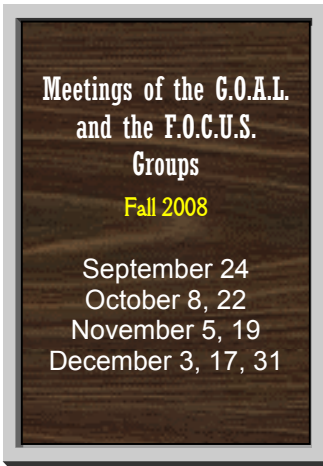
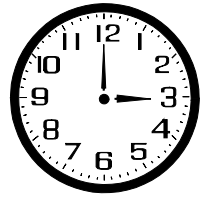


Jonathan does have OCD. He's a bright man, tall, self-possessed, funny, and utterly disabled by a disorder that has steadily taken over his life. He's living at OCDI and doing the hardest work of his life just to quiet the intrusive thoughts and maddening rituals that have been his unwelcome companions since he was 13 years old. If a negative thought—"Is my father going to die?"—intruded while he performed a task, he'd have to repeat the task over and over again until he completed it without the whisper of a bad thought.

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Exposure Therapy at Work

by Mary N., G.O.A.L. Group Member



In June of 2008 I started a new job. As always, I was extremely nervous. A lot of my OCD issues are very present in any type of work that I do, for instance:

1. Taking a bus that will get me to work at least an hour early—"What if the bus breaks down?" "What if the bus is late or doesn't come at all?" "What if I forgot something and have to go back home to get it?" "What if I take a later bus and end up being late?" "What would my supervisor and co-workers think if I'm late?" (These are just a few of the thoughts I deal with constantly.)
2. Always being aware of what I say or do at work—"What if I insult someone?" "What if I'm wrong about something?" "What if I say or do something stupid?" "What if people get upset with me?" "What if people disagree with something I say or do?" "What if I say or do something that makes people think that I think I am better than they are?"
3. Everything must be completely finished before I leave work—"What if I get fired for not having things done in a timely manner?" "What if my supervisor gets upset because I didn't have something done on time?" "What if I forget to do something the next day?"
4. Being the first one at work or at a meeting—"What if I miss something important?" "What if someone wants to talk to me and I'm late?" "What if something important is said and I'm not there to hear about it?" "What if things need to be set up and I'm not there to do it?"

I could go on and on with these questions that constantly plague everything that I do that involves any job that I've ever had. They seem endless. I obsess over these thoughts constantly and believe that the answer to every one of them is simple: I'll get fired.

When I started this job, I came in knowing that everyone I work with will know about my history with mental illness. I am a Certified Peer Specialist. This basically means that one of the reasons I am hired is in order to help other peers with mental illness. Because of this I have shared a little about my own experience with staff. Not only was I open about having Major Depressive Disorder, I was also open about having Obsessive-Compulsive Disorder.

I realized almost immediately that my job was going to be a constant exposure for me. One way that this job is an exposure for me is that things change all the time. Even though we have a certain schedule, every day things would change all the time because "something came up." This was a huge problem with me because I "need" to know exactly what I'm doing every day at every moment when I'm at work. I always became upset when I would just be asked to do something at the last minute.

As I stated earlier, I constantly worry about being late. I quickly discovered that if I went anywhere with my supervisor, that meant I was going to be late. I started avoiding going anywhere with her. I started looking for any type of excuse to leave early and tell her I would meet her there. One day, after I had been working for less than two weeks, I realized that my supervisor was very aware of my issues with being on time. She started asking me to wait for her if we were going somewhere for a meeting. I started thinking that she had somehow found out who my therapist was and had been speaking with him about my OCD. I knew that this thought was not realistic, but I believed it was true. When I would be going somewhere with my therapist, she began talking to me about my OCD. I was very open with her and told her about my "need" to be early for everything. When I told her she smiled and laughed. She then mentioned that going with her to meetings was a real exposure for me. That's when I "knew" she had been secretly speaking with my therapist. I was going out of my way to avoid any type of exposure when at work and my supervisor was providing exposures for me.

Whenever I speak with my therapist about this, he smiles and tells me that I have the perfect job. I spoke to him several times about my supervisor. He always smiles and talks about how much he likes my supervisor. For a long time I was upset about my job situation and hated it when my therapist would tell me what a great job I had. Somewhere along the way I realized that I wasn't as anxious about being on time. The anxiety wasn't completely gone but the obsessive thoughts had begun cutting back. My other issues with OCD and my job also became easier to deal with. This has been all the proof I needed to accept that exposure therapy is the best thing that could have happened for me. ¶

The views expressed in the articles of this newsletter are those of their authors and do not necessarily represent the Philadelphia Affiliate.



Pungent Extracts



I inherited a painting and a violin that turned out to be a Rembrandt and a Stradivarius. Unfortunately Rembrandt made lousy violins and Stradivarius was a terrible painter. **–Tommy Cooper**

I've got all the money I'll ever need if I die by four o'clock this afternoon. **–Henny Youngman**

I feel sorry for people who don't drink. They wake up in the morning and that's the best they are going to feel all day. **–Dean Martin**

My problems all started with my early education. I went to a school for mentally disturbed teachers. **–Woody Allen**

We lived for days on nothing but food and water. **–W. C. Fields**

Only lawyers and mental defectives are automatically exempt from jury duty. **–George Bernard Shaw**

I never read a book before reviewing it. I find that it just prejudices me. **–Sydney Smith**

If you don't clean your house for two months it doesn't get any dirtier. **–Quentin Crisp**

He said it was artificial respiration, but now I find that I am to have his child. **–Anthony Burgess**

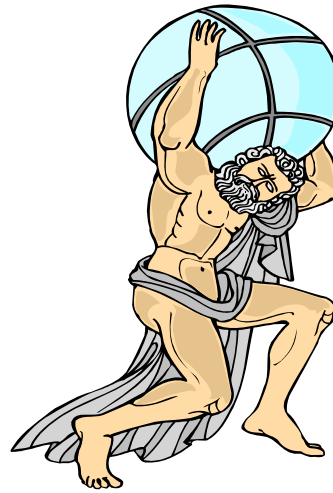
There is more joy in the newspaper world over one sinner who cuts his sweetheart's throat than over the ninety-nine just men who marry and live happily ever after. **–A. P. Herbert**

I have the body of an eighteen-year-old. I keep it in the fridge. **–Spike Milligan**

The music teacher came twice a week to bridge the awful gap between Dorothy and Chopin. **–George Ade**

Canada could have enjoyed English government, French culture, and American know-how. Instead it ended up with English know-how, French government, and American culture. **–John Robert Columbo**

The ideal government is democracy tempered by assassination. **–Voltaire**



Helping to give the reader backbone:

THE SPINAL COLUMN

by Jene Beardsley, Editor

The New-Car Syndrome

Two Christmases ago, a young friend of mine, knowing that I like to hike and explore countrysides, gave me an exquisite compass with my initials engraved on it. It was made by the Dalvey company in the Scottish Highlands. One year later, the friend asked me if I had used it and laughed when I told her it was too good for use and that instead I was keeping it as a showpiece, a kind of heirloom.

Some things, like sunsets, are meant to be admired. Others, like the telephone, are meant to be used. A problem arises with those hybrid things that are meant to be both admired and used.

Everyone knows that a "right from the factory" car depreciates by thousands of dollars once its buyer drives it out of the show room. However, through the weeks and months ahead, once that car accumulates the dings and arrows of outrageous fortune—the scratches and stains and dents of the rough world of use—the owner's pride in it, a kind of innocence, also depreciates.

Perhaps one of the closest experiences a non-obsessive-compulsive has to the obsessive-compulsive experience is his touchiness toward his brand-new car during the "honeymoon" months after its purchase. New-car owners vary in the intensity and the duration of this touchiness. Extreme degrees of it are symptomatic of the obsessive-compulsive disorder. The obsessive-compulsive owner, for example, may be chronically inspecting his vehicle to make sure it's still a virgin and may be tempted to place it in the nunnery of his garage and not use it at all. Another example of such touchiness is in Brad Garret's role in Seinfeld as the mechanic Tony who drives away with Jerry's car because he believes Jerry is not caring for it with perfection.

Most new-car owners, however, like Jerry in this episode, are not stuck at perfection. They come to accept the vulnerability of their machine in the imperfect world of use. But the fact that they have this initial oversensitivity to that vulnerability, the need to protect at disproportionate cost some kind of admirable innocence from useful experience, evidences that the obsessive-compulsive disorder is simply tendencies in normal human nature that have become full-blown in certain gene-jinxed humans. The stigma-happy of the non-OCD world would do well to consider that of a factor can make kindred things seem like different species.

(continued on page 10, column 1)

The G.O.A.L. Post is looking for stories, poems, essays, questions for its professionals, and artwork. Subject matter may relate personal victories, personal defeats dealt with meaningfully, insights, strategies, sources of strength, humor, etc. Writings submitted should be literate (correct grammar, spelling, punctuation, etc.), legible (typed, preferably), and of a reasonable length. All submissions accepted for publication are subject to editorial changes and must be properly attributed to their creators, who will be identified in the newsletter unless they request otherwise. No submissions will be returned. Send them to NE.Muscoat@aol.com.

THE PHILADELPHIA AFFILIATE SERVES AS A CLEARINGHOUSE FOR INFORMATION ON THE OBSESSIVE-COMPULSIVE DISORDER (OCD) AND PROVIDES THE FREE PROFESSIONALLY-ASSISTED SUPPORT GROUPS LISTED BELOW FOR THOSE WITH THE DISORDER.

THE TRICHOTILLOMANIA SUPPORT GROUP IS MEETING EVERY OTHER WEDNESDAY FROM 6:30 TO 7:45 PM IN SUITE 9 OF THE ROSEMONT PLAZA APARTMENTS, 1062 LANCASTER AVENUE, ROSEMONT. FOR MORE INFORMATION TELEPHONE SALLY ALLEN AT 610-525-1510.

A SUPPORT GROUP FOR YOUNG PEOPLE IS MEETING EVERY OTHER THURSDAY FROM 7 TO 8 PM IN SUITE 9 OF THE ROSEMONT PLAZA APARTMENTS, 1062 LANCASTER AVENUE, ROSEMONT. FOR MORE INFORMATION TELEPHONE JUDY KOLMAN AT 610-525-1510.

THOSE SEEKING TO ENTER THE G.O.A.L. SUPPORT GROUP MUST FIRST CONSULT WITH THERAPIST JON GRAYSON. THIS GROUP MEETS AT 8 PM EVERY OTHER WEDNESDAY IN THE ANXIETY AND AGORAPHOBIA TREATMENT CENTER, 112 BALA AVENUE, BALA CYNWYD. THE F.O.C.U.S. FAMILY SUPPORT GROUP IS MEETING IN THE CENTER AT THE SAME TIME. FOR MORE INFORMATION ON THE G.O.A.L. GROUP TELEPHONE THERESA COHEN AT 215-676-3238. FOR MORE INFORMATION ON THE F.O.C.U.S. GROUP TELEPHONE SALLY ALLEN AT 610-525-1510.

GREAT TRUTHS THAT CHILDREN HAVE LEARNED

- 1) No matter how hard you try, you can't baptize cats.
- 2) When your mom is mad at your dad, don't let her brush your hair.
- 3) If your sister hits you, don't hit her back. They always catch the second person
- 4) Never ask your 3-year old brother to hold a tomato.
- 5) You can't trust dogs to watch your food.
- 6) Don't sneeze when someone is cutting your hair.
- 7) Never hold a dust-buster and a cat at the same time.
- 8) You can't hide a piece of broccoli in a glass of milk.
- 9) Don't wear polka-dot underwear under white shorts.
- 10) The best place to be when you're sad is Grandpa's lap.

GREAT TRUTHS THAT ADULTS HAVE LEARNED

- 1) Raising teenagers is like nailing jelly to a tree.
- 2) Wrinkles don't hurt.
- 3) Families are like fudge...mostly sweet, with a few nuts.
- 4) Today's mighty oak is just yesterday's nut that held its ground.
- 5) Laughing is good exercise. It's like jogging on the inside.
- 6) Middle age is when you choose your cereal for the fiber, not the toy.

GREAT TRUTHS ABOUT GROWING OLD

- 1) Growing old is mandatory; growing up is optional.
- 2) Forget the health food. I need all the preservatives I can get.
- 3) When you fall down, you wonder what else you can do while you're down there.
- 4) You're getting old when you get the same sensation from a rocking chair that you once got from a roller coaster.
- 5) It's frustrating when you know all the answers but nobody bothers to ask you the questions.
- 6) Time may be a great healer, but it's a lousy beautician.
- 7) Wisdom comes with age, but sometimes age comes alone.

THE FOUR STAGES OF LIFE

- 1 -- You believe in Santa Claus.
- 2 -- You don't believe in Santa Claus.
- 3 -- You are Santa Claus.
- 4 -- You look like Santa Claus.

SUCCESS

At age 4 success is . . . not peeing in your pants.
At age 12 success is . . . having friends.
At age 17 success is . . . having a driver's license.
At age 35 success is . . . having money.
At age 50 success is . . . having money.
At age 70 success is . . . having a drivers license.
At age 75 success is . . . having friends.
At age 80 success is . . . not peeing in your pants.

--Source Unknown



THE OCD FUNNIES



B.Z. Toons
by Brian Zaikowski

I'M SITTIN' ON TOP OF THE WORLD...

Will someone shut off that damn Jolson song! It's drawing unnecessary attention to me!

Public toilets

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"You'll experience denial, anger, bargaining, depression, acceptance, and finally, stuffing."

No, I don't shave my armpits! I just found a new way to stop pulling the hair on my head!

Yeah? Well, don't get your hops up!

You've checked that entrance rock 10 times, Oogo! It's as snug as it's gonna be. Now come back to bed!

He goes home to change his sheet five times a night!

ARE YOU CRAZY ENOUGH TO SUCCEED?

(continued from page 9)

If he thought about something bad while closing the car door, says Jonathan, "I'd have to close the car door again. If I had an intrusive thought while I was going over a review on an employee, I had to rewrite it."

We all have intrusive thoughts. They flash unbidden across our mental JumboTrons, startling us with their violence, depravity, or just outright weirdness. I'd bet every New Yorker has imagined hip-checking some stranger into the path of an oncoming subway car, and that every Californian has considered, for one brief moment, the idea of plowing his SUV into the jerk in front of him on the Santa Monica Freeway.

For a person living with OCD, thoughts like these are not wadded up and tossed in the recycling bin. Instead, they are pored over, analyzed, and scrutinized for truth.

Imagine this: You've just parked the car. You hop out, grab your bag, and head toward the gym. But wait. Did you lock the car? You head back to make sure you did. Yup, it's locked. Problem solved.

Jeff Szymanski, Ph.D., OCDI's director of psychological services, explains. "Someone with OCD says, 'I went and checked the car, but did I really check it? I'm looking at my hand turning the key in the lock, but is that perception really clear enough? Did I hear the click, or do I just remember hearing the click, or did I hear the click last time I checked this?'"

Shrinks call this pathological doubting, but the person with OCD doesn't need a memo from the Department of Justice to know it's torture.

Looking back, I realize that my OCD began to appear during my senior year of high school, if not earlier. I became convinced that every girl I dated was betraying me. . . . nightly. And so I quizzed them on their whereabouts and demanded alibis for any unexplained absences. Oddly enough, my girlfriends found this suffocating.

My condition confined itself to that strange little corner of my world throughout my college years, and I did just fine. There are some tolerant females out there, let me tell you. But after I graduated, found a job, and moved to New York, I promptly dissolved into a puddle of anxiety.

"The core of OCD and the core of all anxiety is uncertainty. In uncertainty there is the potential for danger," Szymanski says. "OCD really has its field day in stress and in transition. Every time people with OCD go through a change, they're stuck with uncertainty. They want to make themselves certain, and they spend all their time replaying what-if scenarios."

Hell, yeah. I spent 3 years of my life wondering if I had AIDS, hepatitis, and every other infection (despite my no-risk behavior and double-digit blood tests). I called the AIDS hotline so often that a counselor finally yelled at me to get off the phone—"You're worried," he said, "but the guy on the other line is dying." I lost whole days of my young adulthood thinking about what I touched, if I had a cut on my hand when I touched it, or if I'd touched my mouth or eyes before washing. Then I'd replay the whole series of events: Did I wash well enough? Am I sure I didn't have a cut?

I lived in an Escher print.

When I tell Dr. Jenike these details, I don't get the "you freak!" reaction I still brace myself for. "Whatever's the most repugnant to you, that's often what the obsessive thoughts get stuck on," he says. "Like a mother nursing a baby—the mother will think I want to have sex with my baby and be horrified. It seems like OCD is looking for the most repulsive thing to torture people with."

For me, it stopped right there. I never developed the typical hand-washing, repeated-shaving, stove-checking, counting, or touching compulsions. I did not graduate to the level of thinking, "If I do this, then the thing I'm anxious about won't happen." But my girlfriend's suspicions and infection worries were plenty bad enough.

Szymanski suggests thinking about it this way: "OCD rituals sound crazy. But find a place within yourself where you experience a negative emotion so powerful that you're willing to do anything—sell your mother—to get away from that emotion. Even if that behavior makes you look crazy to other people. That's the feeling of OCD."

That feeling finally drove me to a psychopharmacologist, who hit a homer on the first pitch. Prozac wiped out my symptoms within a couple of weeks. I could feel my brain returning to normal.

But most people dealing with OCD require a two-pronged approach of medication (in the form of selective serotonin reuptake inhibitors—SSRIs—like Prozac, Luvox, or Zoloft) and a Kafkaesque form of therapy called exposure and response prevention, or ERP. In ERP, a person learns to tolerate repeated exposure to the very cue that triggers the anxiety without acting out the attending ritual. It's administered in stages, with each stage ratcheting up the exposure.

At OCDI, residents work at dealing with their condition for hours and hours each day, all the while agreeing not to carry out the compulsive behaviors that they once used to temporarily neutralize the power of their thoughts. Each ERP is designed to address a particular obsession or compulsion. Compulsive washers will touch toilets and not be allowed to wash.

Jonathan had to listen to a loop tape, hearing, "I hope my mother will die today" while he pursued activities he enjoyed, "because the thoughts are just thoughts, there's no credence to that happening." He seems agitated and a little rote when he says this, as if the "cure" hasn't quite taken hold.

Repeated exposure to the source of the anxiety, the theory goes, will desensitize a person to it, robbing it of emotional power. In one memorable example, a person with an obsessional fear of stabbing someone was placed in ever greater proximity to knives. Eventually he graduated to standing behind an OCDI staff member for 90 minutes, holding a knife at the ready for a fatal thrust.

No one knows for certain what goes on inside the brain of a person living with OCD, but science is coming much closer to an answer. According to S. Evelyn Stewart, M.D., an assistant professor of psychiatry at Harvard medical school, brain imaging has revealed a biological underpinning for OCD: An overactive loop runs from the brain's decision center (or orbitofrontal cortex) to its movement-governing center (thalamus) and into the basal ganglia, which governs the off switch for thoughts and behaviors.

In primitive times, obsessive-compulsive traits conferred real advantages to humans. Some elementary fear of pestilence and contamination, the prevention of harm, and the concern about necessities probably set the upwardly mobile cave dweller on the route to success.

Similarly, these traits can give you a leg up in today's workplace, as

(continued on page 11)

THE SPINAL COLUMN (continued from page 6, column 2)

The new-car syndrome gives the normal person a better insight into the obsessive-compulsive experience. For him, however, the subject of his oversensitivity is simply a car, and the oversensitivity is temporary. Imagine having this inflamed touchiness as an open-ended attitude toward multiple daily subjects and you will understand better why, as reported in another article in this issue (see page 4), Dr. Jenike's teen-age patient who had severe OCD and also had only five or six months to live because of kidney cancer said, in Jenike's words, "he'd rather get rid of his OCD and live only 6 months, than get rid of the cancer and live with the OCD."

The expression "Use it or lose it" is frequently heard in our society. Cliché or not, it communicates a critical truth. The obsessive-compulsive hides his life away from the chancy world to protect a wrongly admired and illusory innocence. But it is a world which just happens to be considerably accidental that would use his life to exercise out of that life's potential all that is substantially real and justifiably admirable about it: strength and integrity of character, wisdom, dignity, humility, compassion, tolerance, delight, restraint, and the like. These qualities are so much of what makes life meaningful that the degree to which they are lost is the degree to which life itself is lost. The obsessive-compulsive, therefore, needs to ask himself seriously just what is it that he is saving. ¶



New Method Measures Risk for OCD

by Rick Nauert, Ph.D.

Senior News Editor

Psychcentral.com

reviewed by John M. Grobol, Psy.D.

July 18, 2008

courtesy of Paul Stetler, G.O.A.L. Group Member

New research has revealed that measuring activity in a region of the brain could help identify people at risk of developing obsessive-compulsive disorder (OCD).

As the current diagnosis of OCD is based on a clinical interview and often does not occur until the disorder has progressed, the new method could enable earlier detection and intervention.

Cambridge scientists, funded by the Medical Research Council and WellcomeTrust, discovered people with OCD and their close family members show under-activation of brain areas responsible for stopping habitual behavior.

This is the first time that scientists have associated functional changes in the brain with familial risk for the disorder. Their findings are reported in the 18 July edition of *Science*.

Obsessive-compulsive disorder is a debilitating condition that affects 2-3 percent of the population at some point in life. Patients suffer from recurrent intrusive thoughts (obsessions) that are distressing and hard to suppress.

Examples include fears of contamination, or that something terrible will happen to a loved one. They also suffer from repetitive rituals. Examples include hand-washing and checking gas hobs. These symptoms cause distress and can occupy hours during the day, interfering with quality of life and the ability to work.

Although OCD tends to run in families, genetic factors responsible for this heritability are not known. Genes may pose a risk for OCD by influencing how the brain develops.

Dr Samuel Chamberlain at the University of Cambridge's Department of Psychiatry used functional magnetic resonance imaging (fMRI) to measure brain activity in the lateral orbitofrontal cortex (OFC). Located in the frontal lobes, the lateral OFC is involved in decision making and behaviour.

Volunteers were asked to look at two pictures on a screen, each image had a house and a face superimposed. The volunteers were asked to use trial and error to work out whether the house or face was the correct target.

Volunteers pressed a button to indicate which image they believed to be the target, and feedback of 'correct' or 'incorrect' was given on the screen. After the correct target had been identified six times in a row it changed so the volunteer had to learn again. fMRI was used to monitor their patterns of brain activity throughout.

Fourteen volunteers without a family history of OCD, 14 people with OCD and 12 immediate relatives of these patients took the picture test. Later comparison of fMRI images of their brain activity throughout showed under-activation in the lateral orbitofrontal cortex and other brain areas in both the OCD patients and their family members.

Dr Chamberlain, who led the study, explains, "Impaired function in brain areas controlling flexible behaviour probably predisposes people to developing the compulsive rigid symptoms that are characteristic of OCD. This study shows that these brain changes run in families and represent a candidate vulnerability factor.

The current diagnosis of OCD is subjective and improved understanding of the underlying causes of OCD could lead to more accurate diagnosis and improved clinical treatments.

"However, much work is still needed to identify the genes contributing to abnormal brain function in those at risk of OCD. We also need to investigate not only vulnerability factors, but also protective factors that account for why many people at genetic risk of the condition never go on to develop the symptoms." ¶

SUPPORT THE NATIONAL OBSESSIVE-COMPULSIVE FOUNDATION.



On May 21, 2008 Jonathan Grayson (on the far left) appeared on the Oprah Winfrey Show to promote his book *Freedom from Obsessive Compulsive Disorder: A Personalized Recovery Program for Living with Uncertainty*, published by Penquin Books in 2003.

ARE YOU CRAZY ENOUGH TO SUCCEED?

(continued from page 9)

long as you stop shy of the destructive behaviors that mark the disorder. If you tell a job interviewer that you are obsessed with your work, compulsively neat, and utterly scrupulous, chances are you'll impress him or her with your ability and not your insanity. Double-checking a manuscript can prevent you from leaving a critical "I" out of somebody's public-service award. And I challenge you to find a successful salesman who is not more than a little over the top about closing a deal.

Living with the uncertainty

Vladimir Coric, M.D., an associate clinical professor of psychiatry at Yale medical school, runs Yale's OCD research clinic.

He believes that "having some obsessive-compulsive traits can be adaptive in some circumstances and contribute to one's success. If you don't worry about the expectations of your boss and the details of your job, you could be fired. It's appropriate to be obsessive and compulsive about important things. If you're able to turn it on and off, it can be a highly adaptive personality trait. If you're not able to turn it off, as with OCD, it can be highly incapacitating."

Preoccupation with detail is like blood pressure: Too much is bad, as is too little.

Most anxiety disorders tend to skew female. Not so for OCD. Men make up 50 percent of the OCD population and, like me, they tend to develop symptoms earlier in life than women do. And given men's propensity to deny mental disorders, the numbers are probably higher.

But obsessions don't control me anymore. Thanks to chemistry, I've evicted the gnome who forever walked the same path in my mind. The rut he wore has grown over, and my attention no longer sinks into his steps. Still, I've carefully husbanded the obsessive-compulsive traits I like—just enough perfectionism on just the right things, plus a healthy dose of anxiety about my performance and how it is viewed. I rely on them to this day.

Of course, I'm one of the lucky ones. I was able to get help, and then pay for it. Whether others will be as fortunate is now being debated in Congress.

Insurance coverage for mental health improved in the wake of the 1996 Mental Health Parity Act. This federal law mandates that the dollar limits set on health-care coverage for psychological problems equal the limits for problems elsewhere in our bodies. But insurers found plenty of loopholes.

Peter Newbould, the director of congressional and political affairs for the American Psychological Association Practice Organization, says he knows the system still isn't working. "If you've visited your general-practice physician about your backache, and he or she refers you to a chiropractor or orthopedic surgeon, you may pay just 20 percent," he says. The coverage for mental disorders is not nearly as generous. "The system has been rigged for many years in a way that disadvantages mental health," Newbould says.

This is especially true for OCD because it isn't a pop-a-pill kind of condition. Effective treatment for even a mild case requires multiple visits with a specially trained therapist. The good people at Your Insurance Company are delighted to reimburse you for these visits, usually up to a total of, ahem, 50 percent of the cost. Oh, and please don't exceed your maximum visits for the year—as few as 20. If you do undergo enough therapy to get better, the bills will drive you crazy all over again.

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'Mad Pride' Fights a Stigma

(continued from page 3)

Some Icarus Project members argue that their conditions are not illnesses, but rather, "dangerous gifts" that require attention, care, and vigilance to contain. "I take drugs to control my superpowers," Mr. DuBrul said.

While psychiatrists generally support the mad pride movement's desire to speak openly, some have cautioned that a "pro choice" attitude toward medicine can have dire consequences.

"Would you be pro-choice with someone who has another brain disease, Alzheimer's, who wants to walk outside in the snow without their shoes and socks?" said Dr. E. Fuller Torrey, executive director of the Stanley Medical Research Institute in Chevy Chase, Md.

Dr. Torrey, a research psychiatrist who specializes in schizophrenia and manic depression, said he understood the roots of the movement. "I suspect that not an insignificant number of people involved have had very lousy care and are still reacting to having been involuntarily treated," he said.

Many psychiatrists now recognize that patients' candid discussions of their experiences can help their recoveries. "Problems are created when people don't talk to each other," said Dr. Robert W. Buchanan, the chief of the Outpatient Research Program at the Maryland Psychiatric Research Center. "It's critical to have an open conversation."

Ms. Spikol writes about her experiences with bipolar disorder in *The Philadelphia Weekly*, and posts videos on her blog, the *Trouble With Spikol* (<http://trouble.philadelphiaweekly.com/>).

Thousands have watched her joke about her weight gain and loss of libido, and her giggle-punctuated portrayal of ECT. But another video shows her face pale and her eyes red-rimmed as she reflects on the dark period in which she couldn't care for herself, or even shower. "I knew I was crazy but also sane enough to know that I couldn't make myself sane," she says in the video.

In a telephone interview, she described one medication that made her salivate so profusely she needed towels to mop it up. "Of course it's heartbreaking if you let it be," she said. "But it's also inherently funny. I'd sit there watching TV and drool so much, it would drip on the couch."

Ms. Spikol said she has a kind doctor who treats her with respect, and she takes her pharmaceutical drugs to stabilize her mood. "I have asthma, and I use medications to maintain it, too," she said.

Ms. Saks, the U.S.C. professor, who recently published a memoir, *The Center Cannot Hold: My Journey through Madness*, has come to accept her illness. She manages her symptoms with a regimen that includes psychoanalysis and medication. But stigma, she said, is never far away.

She said she waited until she had tenure at U.S.C. before going public with her experience. When she was hospitalized for cancer some years ago, she was lavished with flowers. During periods of mental illness, though, only good friends have reached out to her.


Ms. Saks said she hopes to help others in her position, find tolerance, especially those with fewer resources. "I have the kind of life that anybody, mentally ill or not, would want: a good place to live, nice friends, loved ones," she said.

"For an unlucky person," Ms. Saks said, "I'm very lucky." ¶

A TESTAMENT TO TRANSFORMATION

(continued from page 1)

Everything's just as it was when we brought it here, heaped in piles of plastic bags and boxes, but in my room things are set out in display, hung up in the closet, hung on the walls, everywhere there is something to please the eye. I have what I always wanted, a room that is more than one step to everywhere. There is room to roll my chair around, space to open the dresser drawers. This will be my world, and I will ignore my mother's already cluttered-up rooms. I will simply rejoice in my own room where the wallpaper's not coming off so I look overhead and make shapes from the plaster revealed where the paper's pulled off and there are also no coils of extension cords to make do with having no outlets and only two overhead lights that from time to time snap and crackle ominously. Now I have beauty and light and I must leave my mother to battle her battle with chaos, a battle she's never yet won. But I've won my own with the help of my friend who comes every week and teaches me how to give up, teaches me the value of giving up to make room for myself and the ones that I love. Giving them space means more than keeping everything they gave me or wrote me. So now my room holds only the things that I need, that I truly desire. I'm settled and happy. If only my mother were too. I pray she will open her eyes to the chaos and want to put things away, but I fear I shall have to make do with my room which my friend has taught me to make for myself, not for my things like my mother. II



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ARE YOU CRAZY ENOUGH TO SUCCEED?

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Help may be on the way. In Congress, Sen. Pete Domenici (R-NM), an architect of the 1996 law, has teamed up with Sen. Ted Kennedy (D-MA) to pass the Mental Health Parity Act of 2007, which is now the topic of compromise discussions between the House and Senate. "It is a matter of fundamental fairness that illnesses of the brain are treated on par with other illnesses like cancer, diabetes, and heart disease," says Domenici, who's retiring this year. With any luck, he'll go out with a parity party.

At the end of my day at the institute, I sat with Szymanski, disturbing the feng shui of his neat (obsessively neat, you might say) office. "Here we have patients write their own eulogies. The idea is to project yourself into the future to answer the question, 'What do I want my life to stand for?' People say, 'I want to contribute to the community.' 'I want to be a good person.' 'I want to be connected to my family.' Right, and you spent 4 hours in the bathroom reshaping yourself. How is that connected to your goal?"

By focusing on their lives instead of their anxieties, patients at OCDI learn to live with the sort of uncertainty that used to cripple them. Jonathan is 31 now, 18 years into a battle with OCD that has cost him nearly everything. He is disabled, but perhaps not for long. Three weeks into his stay, he can envision a better future: "I am a highly motivated person, and I function at a very high level even with the severe OCD. So with these tools I'm learning, the sky's the limit. Right now, I'm trying to figure out which parts are the OCD and which parts are me."

An OCD to-do list: Find therapy, or else! II

THE DANGER OF HOARDING

(continued from page 2, column 2)

For example, "They have rambling or overinclusive speech, where you ask them a question and they tell you a whole story with every possible detail before they get to the answer," says Sanjaya Saxena, a professor at UCLA's School of Medicine.

They have high levels of anxiety, depression, and perfectionism. They are greatly indecisive—over what to eat, what to wear. They prepare for all contingencies, keeping items "just in case."

But the true hallmark: "They apply emotions to a range of things that others would consider worthless," says Frost. Where most people see an empty roll of toilet paper, they see art supplies.

At the same time, they tend to be articulate and well-educated, with sophisticated reasons for their saving and acquiring. What if they forgo a newspaper and with it the bit of knowledge that will change their life for the better?

Though people with OCD—those who endlessly wash their hands or check the stove—acknowledge their behavior and are distressed by it, hoarders deny they have a problem.

Brain scans show a difference in brain abnormalities between people with non-hoarding OCD and hoarding OCD, says Saxena of UCLA, who is studying the neurobiology of hoarding.

Whereas non-hoarders show elevated brain activity in certain areas, hoarders show decreased activity in the anterior cingulate gyrus, which deals with focus, attention and decision-making.

Frost is developing cognitive behavioral treatments, but progress is slow. Almost always, if a place is cleaned out, the hoarding behavior returns immediately.

In Pittsfield, Mass., fire chief Stephen Duffy tells of one elderly widow whose house had "debris piled higher than the bed, with one spot where she curled up on the mattress to sleep." II

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