UNDERSTANDING COMPULSIVE HOARDING

"The general public thinks these people are just slobs or lazy, but actually most of the time it's because of not wanting to waste things, and **so** wanting to make the right decision about a thing that it becomes overwhelming and they keep it."

Jason Elias», OCD Institute at Harvard's McLean Hospital OCD Research Program

Categorizing, staying focused and decision-making are extremely difficult for those who hoard.

<u>Perfectionism</u>» is a component as well:

By saving possessions, the compulsive hoarder postpones making the decision to discard something and, therefore, avoids experiencing anxiety about making a mistake or being less than perfectly prepared. The most commonly saved items include newspapers, magazines, old clothing, bags, books, mail, notes, and lists.

(Frost & Gross, 1993; Winsberg et al., 1999).

Read Introduction to Hoarding.(pdf)
Read Hoarding 101.(pdf)
Read Hoarding from the Inside Out.(pdf)
Read How & When to Intervene (pdf)

What IS Compulsive Hoarding?

Hoarding is defined as the **acquisition** of, and **inability to discard** worthless items even though they appear (to others) to have no value.

Hoarding behaviors can occur in a variety of psychiatric disorders and in the normal population, but are most commonly found in people with obsessive-compulsive disorder (OCD). Those people who report compulsive hoarding as their primary type of OCD, experience significant distress or functional impairment from their hoarding.

They have symptoms of **indecisiveness**, **procrastination**, **and avoidance**, are classified as having compulsive hoarding syndrome. An estimated 700,000 to 1.4 million people in the United States are believed to have compulsive hoarding syndrome.

Compulsive hoarding is not just an enthusiast's passion for collecting stamps, dolls, or baseball cards. Neither is it someone who likes to "tinker," and fix up old cars or broken furniture. People with compulsive hoarding syndrome may have **immense difficulty throwing anything away**, from the oldest paper clip, to a used food container, to an out-of-date newspaper, for **fear** that they might need those items in the future. Their homes are often full of stuff that the rest of us would call "junk." The most commonly saved items include newspapers, magazines, old clothing, bags, books, mail, notes, and lists.

Hoarding and saving symptoms are part of a discrete clinical syndrome that also includes indecisiveness, perfectionism, procrastination, difficulty in organizing tasks, and avoidance.

(Frost & Hartl, 1996; Steketee & Frost, 2003).

Along with difficulties in throwing things away, compulsive hoarders have severe difficulties making decisions, <u>perfectionism</u>, and avoiding tasks. People with compulsive hoarding syndrome do **not like to make mistakes**. To prevent making a mistake, **they will avoid or postpone making decisions**. Even the smallest task, such as washing dishes or checking mail may take a long time because it has to be done "right." The net result of these high standards and the fear of making a mistake is that compulsive hoarders avoid doing many tasks, because everything becomes tedious and overwhelming. 1

"Let's start by defining hoarding as a mental health problem. We realize that these words might be hard for some people to swallow. For some, the words conjure up very unpleasant (maybe even scary) images of serious mental illnesses such as schizophrenia.

Some people with compulsive hoarding do have these kinds of problems, but most don't and won't. We don't mean in any way to imply that having a mental health problem means that you are "crazy," "damaged," or a "hopeless case." Quite the contrary: **many people with compulsive hoarding are smart, witty, and delightful**, even though we are well aware that they are suffering.

What we **do** mean is that people with compulsive hoarding are not fully in control of their behavior. They didn't sign up for this. They are hooked into a pattern of behavior that even they cannot fully understand or manage."

-David F. Tolin PhD, Anxiety and Research Center, Hartford, CT

Are "Hoarders" the Same As "Collectors"?

Hoarding is not the same as collecting.

Generally speaking, **collectors are proud** of their possessions and enjoy showing them off. An avid car collector would enjoy driving his vintage sports car around the block; a boy who collects baseball cards would be proud to show them to his friends. Collectors often find joy in their collection and go out of their way to impress others. They make reference to their collection during conversation or go to conferences to meet others with similar interests.

Collectors often have a specific location in the home for their collection. The child who collects baseball cards may have his cards in a special folder. Others may have their collection of stamps, cameras, figurines, or dishes laid out in a hutch or bookcase where viewing them is easy. Additionally, collectors budget and save their money to accommodate the purchase of new items and feel satisfied when adding them to the existing collection.

If you are a **hoarder, however, you may be embarrassed by your possessions.** You purchase items with the intention of finding some function for them but end up feeling embarrassed by them. When one item is purchased, another will follow, followed by another and so on until there are more items than places to put them. This process usually results in clutter.

Clutter is the product of either having too many items with not enough storage or feeling overwhelmed by the possessions and not knowing where to put them. Of course, you may hoard and not have clutter because you organize everything and put it away. However, most people who hoard do have clutter.

It is fairly common for **hoarders to be so embarrassed** by their possessions that they try to dissuade people from coming over to their homes. You may prefer to meet people at restaurants rather than having friends over for meals. This is the exact opposite of collectors.

Hoarders prefer to purchase new appliances when the old ones break, because the thought of having repairmen at the house is too overwhelming. Steve, a hoarder for fifteen years, confessed that he did without a refrigerator for three years because he could not let anyone in his home to repair the one that broke, and he could not have a new one delivered because there was no space for it. As you can see, although there are a few overlapping qualities between hoarders and collectors, there are plenty of differences too.

Summary:

COLLECTORS

- Feel proud of their possessions
- Keep their possessions organized and well maintained
- Find joy in their possessions and willingly display them to others
- Attend meetings or conferences with others who share their interest
- Enjoy conversations about their possessions
- Budget their time and money around their possessions

HOARDERS

- Feel embarrassed by their possessions
- Have their possessions scattered randomly, often without any functional organization
- Have clutter, often resulting in the loss of functional living space
- Feel uncomfortable with others seeing their possessions, or outright refuse to let others view their possessions
- Often have debt, sometimes extreme
- Feel ashamed, sad, or depressed after acquiring additional items. 3

What Are The Reasons Why People Hoard?...

Information-processing deficits:

including deficits in decision making, deficits in organizational skills, and difficulties with memory functions;

Problems in forming emotional attachments:

compulsive hoarders believe that their belongings are a part of them, so discarding an item is like discarding a part of themselves; (See also: <u>Anthropomorphism</u>)

Behavioral avoidance:

the net result of poor decision-making skills and the need for perfection. Compulsive hoarders avoid not only the decision to discard an object, but also what to do with the object once they have it; and,

Erroneous beliefs:

about the nature of possessions: such as beliefs about the necessity of

maintaining control over possessions, beliefs about responsibility for possessions, and beliefs about the necessity of perfection. 2

OCD is often described as "a disease of doubt." Sufferers experience "pathological doubt" because they are unable to distinguish between what is possible, what is probable, and what is unlikely to happen.

-National Alliance on Mental Illness

So it's a form of Obsessive-Compulsive Disorder, like hand-washing & checking things?

Although Compulsive Hoarding can be a symptom of other disorders, it is currently classified as a **subtype of obsessive-compulsive disorder** (OCD).

The <u>diagnostic status of compulsive hoarding is uncertain</u>. Hoarding is a problem often seen in people with obsessive-compulsive disorder (OCD). It can be associated with any number of other disorders including schizophrenia, dementia, anorexia, depression and even the so called <u>Diogenes syndrome</u>.

Compulsive hoarding has enough in common with other forms of OCD to be classified as a variation of this disorder with **some features of impulse control disorders.** This particular variety of OCD is common and can be severe and quite difficult to treat. Ultimately, research may clarify questions about differences in neurobiology or genetics of varieties of OCD and tell us where hoarding best fits. 4

You may be wondering how OCD and hoarding are related. Most of the research suggests that hoarding is a symptom of OCD, yet only 25 to 35 percent of individuals with OCD actually hoard (Frost/Steketee-98).

It is associated with OCD mostly because hoarders have obsessions about their possessions, compulsions to hoard, and doubt about what to discard.

Hoarders may think a lot about their possessions. They may wonder where something was placed, whether something was accidentally thrown out, whether someone touched their belongings, or how to organize their possessions. They may find it hard to resist the urge to save and to not discard. Throwing things out causes great distress, and they avoid the distress by hoarding.

Hoarding is a compulsion that reduces the uncomfortable feelings, and thus is a form of OCD.

Compared to non-hoarding OCD patients, hoarders score higher on anxiety, depression, dependent and schizotypal personality disorder symptoms, and family and social disability. Our group found that compulsive hoarders had significantly higher anxiety and lower global functioning than non-hoarders. They did not respond as well to intensive, multi-modal treatment as non-hoarding OCD patients.

-Sanjaya Saxena, M.D.Z

Do Compulsive Hoarders Have Different Brain Patterns Than Other OCD Sufferers?

From Sanjaya Saxena, M.D.:

Our group recently conducted a positron emission tomography (PET) brain imaging study that measured cerebral glucose metabolism. This is a measure of brain activity in patients with the compulsive-hoarding syndrome. It was compared with non-hoarding OCD patients and controls without any psychiatric disorder.

We found that compulsive hoarders had a unique pattern of brain activity that was distinct from that seen in either non-hoarding OCD patients or controls. Compulsive hoarders had significantly lower metabolism in the posterior cingulate gyrus and occipital cortex. A brain region involved in visual processing compared to controls. Whereas non-hoarding OCD patients had significantly higher glucose metabolism in bilateral thalamus and caudate, structures previously found to have elevated activity in OCD.

Hoarders and non-hoarding OCD patients also differed from each other. Hoarders had significantly lower metabolism in the dorsal (superior) part of the anterior cingulate gyrus and thalamus than non-hoarding OCD patients. Across all OCD patients studied, hoarding severity was significantly correlated with lower activity throughout the dorsal anterior cingulate gyrus.

Our findings suggest that the **compulsive-hoarding syndrome may be a neurobiologically distinct variant of OCD.** In addition to the observed differences in cerebral glucose metabolism, our results raise the question of whether compulsive hoarders also have structural brain abnormalities and neurocognitive deficits that differ from those seen in non-hoarding OCD patients. 7

Hoarding seems to run in my family...will I "get it?"

An <u>OCD Collaborative Genetics Study</u> was done by the Department of Psychiatry and Behavioral Sciences, **Johns Hopkins University School of Medicine** in March, 2007. Their findings suggest that a region on

chromosome 14 is linked with compulsive hoarding behavior in families with OCD.

<u>Sanjaya Saxena, M.D.,</u> Director of the UCSD Obsessive-Compulsive Disorders Program says in a <u>letter to the editor</u> of the American Journal of Psychiatry;

"The OCD Collaborative Genetics Study is the third study to find genetic markers specifically associated with compulsive hoarding, indicating that it is a distinct and heritable phenotype. Other studies have confirmed that compulsive hoarding is strongly familial $(\underline{5})$ and appears to breed true $(\underline{6})$."

Cristina M. Sorrentino, PhD, MSW, says on the <u>OCF Hoarding website</u>:

There is some evidence that compulsive hoarding has a genetic cause. For example it often runs in families, although this may also mean that hoarding behaviors and beliefs are learned.

Sanjaya Saxena, M.D., says:

Genetic and family studies suggest that compulsive hoarding has a different pattern of genetic inheritance and comorbidity (coexisting illnesses) than other OCD symptom factors. **The hoarding/saving symptom factor has a recessive inheritance pattern,** whereas the aggressive/checking and symmetry/order symptom factors show a dominant pattern.

A genomewide scan conducted in sibling pairs with Tourette's Syndrome (in which there is a very high prevalence of OCD symptoms) found that the hoarding/saving symptom factor was significantly associated with genetic markers on chromosome 4, 5, and 17. One study found that 16 of 19 OCD patients with prominent compulsive hoarding (84%) reported a family history of hoarding behaviors. In at least one a first-degree relative, while only 37% reported a family history of DSM-IV OCD.

A family study of OCD found that, compared with people with non-hoarding OCD, compulsive hoarders had a greater prevalence of social phobia, personality disorders, and pathological grooming disorders, These were trichotillomania, skin-picking, and nail-biting, and higher rates of hoarding and tics in first-degree relatives. These studies indicate that the compulsive hoarding syndrome may represent a distinct subgroup or variant of OCD that may be caused by different genetic and familial factors than non-hoarding OCD. 7

Randy Frost, PhD, says in the Spring 2007 New England Hoarding Consortium Newsletter:

In our first studies of hoarding we noticed a trend for this syndrome to run in families. Since then three genetics studies have appeared in the research literature, all suggesting that hoarding may be at least partly heritable. These studies start with select populations, like Tourette's patients or OCD patients, and look for people who hoard.

One of these studies was done by the <u>OCD Collaborative Genetics Study</u> under the direction of investigators at the Johns Hopkins University Medical School. They found preliminary evidence that the genetic contribution to hoarding could be localized to a specific chromosome on the DNA chain. Something at chromosome 14 may be associated with hoarding. This could be a dramatic breakthrough in our understanding of hoarding.

However, it is important to note that these studies are all preliminary with relatively small samples that don't fully represent the range of hoarding in the population. Furthermore, we also don't yet understand just what traits might be heritable. Perhaps it is something that underlies hoarding, like decision-making problems, and not hoarding itself that is inherited.

To more fully determine the heritability of hoarding a much larger study is needed, one drawn from the entire population of people who hoard. That is, the sample must represent all people with hoarding problems and not just those who are already diagnosed with OCD. To that end, we have joined forces with the Johns Hopkins group to study the genetics of hoarding. Our first attempt to obtain funds from NIMH for the project failed, but we will be trying again shortly.

At this point we have no markers for the development of hoarding. **We don't know who will and who won't develop hoarding problems.** The best advice we can give is to be open and honest with your children as they grow up about hoarding tendencies in the family. People who can recognize and talk about their own hoarding problems are much better able to control them than people who can't. -R.Frost

Dr. Tolin:

While Dr. Tolin says people may be predisposed to compulsive hoarding, they most likely did not inherit it. "For a condition like compulsive hoarding to come about you probably have to have a person who has a certain set of inherited characteristics," he says. "[But] then that person then has to in some way learn or pick up the behavioral pattern." People can overcome their predisposed tendency to be messy or to hoard, Dr. Tolin says. "Biology is not destiny. Just because somebody has a genetic predisposition to develop a certain behavioral condition, that doesn't mean they are doomed," he says.

Exactly what triggers hoarding compulsions and desires is still under investigation.

Like OCD, it may be related, at least in part, to genetics and upbringing.

-Mayo Clinic

Can It Be Treated?

There are two types of treatment that have been proven to be effective for OCD and are considered standard. They are front-line treatments: pharmacotherapy (treatment with medications) and cognitive-behavioral therapy (CBT), using the technique of exposure and response prevention (E&RP). 7

Cognitive behavior therapy is the most common form of psycho-therapy used to treat hoarding. As part of cognitive behavior therapy:

- >Explore why feel compelled to hoard
- >Learn to organize and categorize possessions to help decide which ones to discard
- Declutter home during in-home visits by a therapist or professional organizer
- >Learn and practice relaxation skills
- >Attend group therapy
- >Be encouraged to consider psychiatric hospitalization if hoarding is severe
- >Have periodic visits or ongoing treatment to help keep up healthy habits-Mayo Clinic>
- •5 Stages of Change for Compulsive Hoarding
- »Motivation and Compulsive Hoarding Treatment
- »How is it treated?
- »Is there a cure?
- »Problems in treating it
- »What to expect in treatment
- »How to know if your therapist knows how to treat OCD?
- »Intensive Treatment Programs for OCD
- »Understanding Treatment Options

Some tools:

Cost-Benefit Analysis

Dysfunctional Thought Record

Subjective Units of Distress

Questions to ask while decluttering

Goals of therapy for hoarders:

-- Avoid repeatedly asking: "Why? Why do I hoard?" Recovery doesn't require an answer to "Why?" Remember: obsessive-compulsive disorder is not logical. Ask instead: "What is my objective? How can I best get there?"

- -- Develop an ability to tolerate intense emotions. Rate intensity of feelings on a scale of 1 to 10. Observe changes in intensity of feelings. Notice that feelings come and go; saving things is not required to reduce anxiety.
- -- Only Handle It Once. Deal with each item only once as soon as it comes into the house, instead of storing items to check more thoroughly later. Do not retrieve items from the trash when second thoughts raise doubt.
- -- Simplify decision-making. Limit choices, (e.g., keep, recycle, sell, give or throw away). Make clear decision rules for each choice, (e.g., keep only 10 plastic bags, dispose of or recycle others). Use broad categories instead of many specific ones. Accept that others, including experts, may do things differently.
- -- Buy and keep "just enough." Sales will be repeated. If you run out, it is not a disaster. Keep items you use, dispose of others.
- -- Focus on functionality. Select a target, for example, an area such as the kitchen or a corner of a room. "Excavate" the target by throwing away and organizing items. Maintain clear space. Use the cleared space only for its intended purpose.
- -- Seek assistance or another opinion. Hoarders have a hard time determining what is "important vs. unimportant," "just enough vs. excessive" or "necessary vs. inconsequential." Seek guidance from a friend or professional. Persevere with your goals. -Source

The more people who Hoard that will dare to step forward to seek treatment, the better the treatments will become since this means that there will be more cases to be studied, more facts to look into. Also, the higher the number of sufferers, the more the Medical World will become interested to help and find cures with more money backing up the research projects.

By raising popular awareness and asking for professional help some of the shame may finally start to lessen and solutions start to increase.

-UOCHD website»

Are There Medications for it?

Initial studies suggest that antidepressants offer little help for hoarding. "More research has yet to be done trying other types of drugs," <u>Steketee said</u>.

Sanjaya Saxena, M.D. says:

Effective medication treatments for OCD include the serotonin reuptake inhibitor (SRI) medications. These are citalopram (Celexa), escitalopram (Lexapro), fluoxetine (Prozac), fluvoxamine (Luvox), paroxetine (Paxil), and sertraline (Zoloft). The tricyclic antidepressant clomipramine (Anafranil), which also strongly inhibits the reuptake of serotonin.

The compulsive hoarding syndrome, has often proven refractory to treatment with these standard medications.

In several studies of OCD treatment, hoarding and saving compulsions have been strongly associated with poor response to SRIs. A small study using open treatment with paroxetine or CBT for OCD patients found that nonresponders were significantly more likely to have hoarding/saving symptoms than responders. Hoarding and saving symptoms were a significant predictor of nonresponse.

Another case series described treatment response in 18 compulsive hoarders treated openly with a variety of SRIs. Only one of the 18 had a marked response. Nine had partial responses; and nine had minimal or no response. In an analysis of large-scale, multicenter, controlled trials of SRI treatment for patients with OCD, higher scores on the hoarding symptom dimension predicted poorer response to SRI treatment, after controlling for baseline severity.

Compulsive hoarding is a clear predictor of poor response to standard anti-obsessional medications. Despite this fact, no prior medication treatment study has specifically targeted the compulsive-hoarding syndrome. 7

Read more about: Neurobiology and Medication

How Can I Help My Hoarding Loved One?

Unfortunately, we (childrenofhoarders.com) don't have the answer to this, but we can offer advice from others who have tried:

- •A letter to a mother, from her daughter
- <u>•Advice on How to Help</u>, shared from a daughter of a father that hoards, in the <u>Messiness&Hoarding »Support Group</u>. Posted here with the permission of Sandra Felton, Founder of Messies Anonymous»
- Advice on how to communicate with a Hoarder, from a spouse, shared in the Mates of Messies support group. Posted here with the permission of author.

»How to help someone you care about

How Can I Get My Hoarding Loved One Get Motivated To Want To Change?

<u>Some ideas collected by childrenofhoarders.com from visitors/other.</u>

Quote about Motivation and Discrepency

Dr. Randy Frost speaking during <u>Face Your Hoarding Tendencies teleclass</u>, March 8, 2007. Minutes 24:35 & 26:16 of recorded discussion: "Regarding motivation, there are a couple of things that I think it's important for people to think about. And that is in order for change to happen in anyone's life, two things have to happen.

One is the change has to be important. Now what I mean by important is that there has to be a discrepancy or a difference between the way the person is living now and the way they want to live. There's got to be some discrepancy there.

So the person's unhappy with the way they are now. The idea is that if you haven't reached your goal, but if you're reasonably comfortable and there's not much difference, then change is unlikely. There's got to be a big enough discrepancy between where you're at now and where you want to be in order for that change to be important.

But beyond that, the second thing we have to have is some confidence that change is possible. If there's a discrepancy between the way I live now and the way I want to live but I don't have any confidence that I can actually make a change, then what's going to happen is I'm going to engage in some funny ways of thinking in order to reduce that discrepancy. I'm going to start telling myself, ;

"Well it's not so bad the way it is now." Or, I'm going to tell myself "that maybe I like it this way." Or I'm going to tell myself "it's not my problem, it's someone else's problem. Because I have this discrepancy and I have to reduce it in order to feel comfortable. And I can't reduce it by changing because I'm not confident that I can do it. So I use some mental trickery and that leads me to appear as though I don't recognize that I have a problem."

Additional Reading

Cognitive-behavioral model of compulsive hoarding

Current cognitive-behavioral conceptualizations of compulsive hoarding view hoarding as the result of one or more of these four deficits:

Information-processing deficits

including deficits in decision making, organizational skills, and memory. Compulsive hoarders often fear making mistakes, and as a result, they often avoid or postpone making decisions.

Even the smallest task, such as washing dishes or checking mail, can take a long time because it has to be done "just right." If something is to be filed, it must be filed under the "perfect" category. If something is to be given away, it must be given to "just the right" person or organization. The net result of these **high standards** and the fear of making a mistake is that compulsive hoarders avoid doing many tasks, such as reviewing the mail and making decisions about what to do with each item; the result is that the mail (and other things) pile up, and the hoarder is unable to tackle the problem, including beginning the process of throwing away;

Problems in forming emotional attachments

Compulsive hoarders often believe that their belongings are a part of them/someone else, so discarding an item is like discarding a part of themselves/others

Behavioral avoidance

The net result of poor decision-making skills and the need for perfection. Compulsive hoarders avoid not only the decision to discard an object, but also what to do with the object once they have it. Because of their desire for perfection, compulsive hoarders frequently take a long time to do even small chores. An inordinate amount of time may be spent "churning" - moving items from one pile to another but never actually discarding any item nor establishing any consistent organizational system.

Erroneous beliefs about the nature of possessions

Beliefs about the necessity of maintaining control over possessions, beliefs about responsibility for possessions, and beliefs about the necessity of perfection. For example, a compulsive hoarder will think, "This is too good to throw away,""This is important information," "I will need this later," "This should not be wasted."

We all have these thoughts from time to time, but those with compulsive hoarding syndrome have them more often and have more anxiety and distress associated with them. If they have any doubt at all - no matter how trivial, compulsive hoarders will keep it -- just in case. The default is always to keep.

Cognitive-behavior therapy for compulsive hoarding

Cognitive-behavior therapy (CBT) for compulsive hoarding, which has included mainly strategies demonstrated to be successful in treating obsessive-compulsive disorder, has been for the most part ineffective. However, cognitive-behavior therapy that has been **tailored specifically to the unique characteristics of compulsive hoarders** shows promise, although treatment is usually much longer than the treatment of non-hoarding OCD.

CBT focuses on the four areas mentioned above and is directed towards: Decreasing clutter; Improving decision-making skills and improving organizational/sorting techniques.

Treatment interventions used include decision-making training, exposure and response prevention, and cognitive restructuring.

*Much of the information above was adapted from SF Bay Area <u>Center for Cognitive Therapy</u>»

Randy O. Frost, Ph.D.,

"The acquisition and failure to discard possessions that appear to be useless or of limited value. This describes the behavior that many of us engage in. It is not really a problem, maybe an eccentricity, unless we see the other two features of the definition: Living spaces so cluttered that using the room as intended is impossible.

The third defining feature is significant distress or impairment in the ability to function. People experience distress at the possibility of throwing things away, and at the Herculean effort it would take to clean up the house. They develop avoidance to decision-making and discarding. They avoid putting things out of sight. We think hoarding behavior is in large part an avoidance behavior.

-Randy O. Frost. Ph.D., Speaking to the New York City Hoarding Task Force, 94.

Dr. Randy Frost, the Israel Professor of Psychology at Smith College, has authored over 100 scientific articles and book chapters mostly concerning perfectionism, and obsessive-compulsive disorder, and hoarding. He is a registered expert on Compulsive Hoarding.

Dr. Frost holds two NIMH-funded grants jointly with Gail Steketee, Ph.D. and David O. Tolin, Ph.D., to study compulsive hoarding, and is a member of the Hoarding of Animals Research Consortium (HARC) and New England Hoarding Consortium.

He has consulted with numerous communities in setting up and running task forces on the problem of hoarding, including New York City, Ottawa, Canada, and Northampton, Massachusetts.

His work has been featured on news programs such as 20/20, Dateline, Good Morning America, and NPR. In1993, he published the first systematic study of compulsive hoarding.

Audio

Hoarding and Clutter By The Infinite Mind This audio program from the non-profit radio show, The Infinite Mind looks at hoarding, which involves the accumulation of, and inability to throw away, unneeded possessions - to the point that a home may become so filled with stuff that furniture and rooms can no longer be used for their intended purposes.

Guests include Dr. Randy Frost, a pioneer researcher in the study of clinical hoarding, and Dr. Sanjaya Saxena, a neurobiologist who is pinpointing where in the brain the problem seems to originate. Author Denise Linn, addresses non-clinical forms of hoarding with tips on how to recognize - and get rid of - clutter.

Gail Steketee, Ph.D.

Gail Steketee, PhD, Professor at the Boston University School of Social Work, has conducted a multiple research studies of OCD and its spectrum conditions, including body dysmorphic disorder and the nature and treatment of compulsive hoarding.

"They may have some depression, some anxiety," she said, "but mostly they're attached to their things in ways that make it very difficult to get rid of them. But it may well be that hoarding is actually closer to an "impulse control disorder," like gambling, because those who hoard often experience active pleasure as they acquire or pile up their possessions," Steketee said.

"Hoarding can involve emotions -- feeling safer among walls of clutter, for example. And thoughts -- like, "I'm sure I could use that broken tape deck someday!" And even unconscious values, like "More is better." -Gail Steketee, Ph.D. Source»

With colleagues Randy Frost, PhD. and David Tolin, PhD., she holds two NIMH-funded grants to study diagnostic and personality aspects of compulsive hoarding, and test a specialized cognitive and behavioral treatment for this syndrome.

Additional research interests include the study and treatment of compulsive hoarding of animals under the auspices of the Hoarding of Animals Research Consortium (HARC). She has published over 150 articles, chapters and books on OCD and related disorders. Her most recent books are by Oxford University Press -- Compulsive Hoarding and Acquiring: Therapist Guide and Workbook (Steketee & Frost) and Buried

in Treasures: Help for Compulsive Hoarding (Tolin, Frost & Steketee).

»Her Faculty Profile at Boston University

»Online video presentation she did about Compulsive Hoarding

»Obsessive Compulsive Foundation Hoarding Website (co-editor)

New England Hoarding Consortium

Spring 2006 Newsletter

Spring 2007 Newsletter

<u>Chapter 23</u> about Hoarding in OCD book by Jenike

Her books on Compulsive Hoarding:

»Buried in Treasures

<u>»Workbook</u>

»Review

»Treatments That Work, Compulsive Hoarding and Acquiring, Therapists Guide

»News Article: The Boston Globe 4/2/07, <u>"Buried Alive".</u> Ouote from article above:

"Pathological hoarding is far more than mere messiness or a pack-rat tendency," said hoarding specialist Gail Steketee, interim dean of the Boston University School of Social Work. The people she and her colleagues treat and study tend to have reached the point where they lose whole rooms to piles of what to them are treasures and to anyone else looks like trash.

"Their homes are often tagged as potential threats to public health. Yet otherwise, most tend to function fairly normally out in the world," said Steketee, who has coauthored a new book, "Buried in Treasures," that translates the therapy program for the lay public. "They may have some depression, some anxiety," she said, "but mostly they're attached to their things in ways that make it very difficult to get rid of them.

But it may well be that hoarding is actually closer to an "impulse control disorder," like gambling, because those who hoard often experience active pleasure as they acquire or pile up their possessions," Steketee said. "Hoarding can involve emotions -- feeling safer among walls of clutter, for example. And thoughts -- like, "I'm sure I could use that broken tape deck someday!" And even unconscious values, like "More is better."

Initial studies suggest that antidepressants offer little help for hoarding. "More research has yet to be done trying other types of drugs," Steketee said. The treatment she has developed with her colleague, Randy O. Frost of Smith College, attacks hoarding from several directions. It fosters skills at decision-making, sorting, and organizing and provides plenty of supervised practice at decluttering so hoarders can keep at it on their own after therapy ends. It also tries to address the deep-seated emotions that make it so hard to let go of things.

About half of the their clients have gotten significantly better, Steketee said, rising from perhaps a 7 to a 3 on a photo test to determine their level of clutter, from pure neatness (1) to total chaos (9). That is not bad for a notoriously difficult problem, said Elias of McLean, who is not involved in Steketee's research. Hoarding is one of the most recalcitrant symptoms of obsessive-compulsive disorder.

David F. Tolin, Ph.D.

Dr. Tolin is the founder and Director of the Anxiety Disorders Center at The Institute of Living in Hartford, CT.

The author of over 70 scientific journal articles, Dr. Tolin's research and clinical interests include the nature and treatment of anxiety disorders, obsessive- compulsive disorder and related conditions such as hoarding.Dr. Tolin is a co-investigator with Drs. Frost and Steketee on two federally funded research projects investigating compulsive hoarding; he is also the principal investigator on a study using neuro-imaging to study hoarding. Dr. Tolin has been a recurrent guest, discussing compulsive hoarding, on Good Morning America and The Oprah Winfrey Show.

"Characterized by difficulty parting with objects as well as clutter to the point of functional impairment, hoarding is often associated with attention deficit hyperactivity disorder, generalized anxiety disorder, major depressive disorder and obsessive compulsive personality disorder," Tolin said. But because many hoarders show few other signs of OCD, Tolin and some other researchers believe hoarding may soon become a disorder in its own right."

»His Website

New England Hoarding Consortium

Spring 2006 Newsletter

Spring 2007 Newsletter

His Book:

<u>»Buried in Treasures:</u> Help for Compulsive Acquiring, Saving, and Hoarding By David F. Tolin, Randy O. Frost, Gail Steketee

<u>»Click here</u> to listen to Dr. Tolin's interview about compulsive hoarding with Psychjourney Podcasts.

»Click <u>here</u>to view Dr. Tolin's discussion about compulsive hoarding on ABC News Medical Mysteries.

Click <u>here</u>» here to view Dr. Tolin's first discussion about compulsive hoarding on Good Morning America and click <u>here</u>» to view his second segment on GMA.

»The $\underline{\text{first installment}}$ of Dr. Tolin's discussions about compulsive hoarding on The Oprah Winfrey Show.

»Dr. Tolin's Resource Guide for Compulsive Hoarding

Sanjaya Saxena, M.D.

Dr. Saxena is the Director of the UCSD Obsessive-Compulsive Disorders Program. His research focuses on the neurobiology and treatment of obsessive-compulsive disorder (OCD) and related disorders. He uses functional and structural brain imaging to understand the brain circuits that mediate OCD symptoms, to reveal how effective treatments work in the brain, and to predict response to different types of treatments.

Recently, Dr. Saxena has been studying specific subtypes and variants of OCD, such as Compulsive Hoarding, to understand their neurobiology and develop better treatments for

these disabling conditions. He has received research grants from the NIMH and the Obsessive-Compulsive Foundation.

"In the brain of compulsive hoarders was a unique, distinct pattern. They did not have the typical areas of elevated activity we saw in all the other OCD patients, instead they actually had low activity in certain parts of the brain that were involved in visual-spatial orientation, and in other parts of the brain involved in tension, motivation and decision-making."

-Sanjaya Saxena, M.D. Source»

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Q & A with professionals in this field of research

- »Q & A from the Obsessive Compulsive Foundation Hoarding Website.
 »Q & A from the OC Foundation (Online Information Packet)
- New England Hoarding Consortium:
- Spring 2006 Newsletter Go to pages 5 & 6 (pdf)
 Spring 2007 Newsletter Go to pages 6-8
- »Dr. Randy Frost Discusses This Quiet Obsession-Q & A with 20/20 ABCNews.com
- Q. My elderly friend has a serious clutter problem. She can't throw things away or organize them, and her apartment is so stuffed that it is hard to get around. She has tried herbs, hypnosis, and sessions with so-called experts, but nothing works. Could you explain this problem and describe how she can be helped?

Α.

»8/21/2006-Harvard Health Publications

By Michael Craig Miller, M.D. Editor in Chief

»7/9/2007-Psychology Today Hoarding: Trash as Treasure

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Beliefs/Attachments-Emotional Reactions

Information processing deficits:

Perception Attention Memory Categorization Decision-making Early experiences

Core beliefs:

Unworthy Unlovable Helpless

Personality traits:

Perfectionism Dependency Anxiety sensitivity Paranoia

Mood:

Depression Anxiety

Comorbidity:

Social phobia Trauma

Clutter/Beliefs about possessions:

Instrumental value (has a use)
Intrinsic beauty
Sentimental value

Positive emotions:

Pleasure Pride

Beliefs about vulnerability:

Safety/comfort Loss

Beliefs about responsibility:

Waste Lost opportunity

Beliefs about memory:

Beliefs about control Mistakes Lost information

Negative emotions:

Sadness/grief Anxiety/fear guilt/shame Acquiring Difficulty discarding Saving

»Source: Chapter 1, Treatment Guide for Clinicians (Frost/Steketee)

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Degrees of Compulsive Hoarding

»Degrees of Squalor by Squalor Survivors»

»Clutter Hoarding Scale by National Study Group on Chronic Disorganization»

Measures on a scale from 1 to 5, four dimensions (Structure & Zoning Issues, Pets & Rodents, Household Functions, and Sanitation & Cleanliness)

»Measurement of Compulsive Hoarding Survey

A survey for measuring the degree of compulsive hoarding in an individual based on 23questions. The survey has three sub-scales to measure clutter, difficulty in discarding and saving, and acquisition.

»Clutter Image Rating

(from online materials available with Treatments That Work: Compulsive Hoarding and Acquiring workbook. (Will need user name and password from book purchase to access.) Images of a progressively

cluttered/messy/hoarded room are presented for comparison.)

<u>»Livingroom</u>

<u>»Kitchen</u>

»Bedroom

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5 Stages of Change For Compulsive Hoarding

People can and do change, either by themselves or with the help of therapy, either self directed or with the assistance of a therapist. James Prochaska, Ph.D, and his colleagues have spent years studying and researching how people change and they have determined that people change in stages.

They define these stages as

- 1) PRECONTEMPLATION
- 2) CONTEMPLATION
- 3) PREPARATION
- 4) ACTION
- 5) MAINTENANCE

The Five Stages of Change* for compulsive hoarding are:

PRECONTEMPLATION

In this stage, you are essentially unaware that a problem exists and, as a result, have no intention of changing your behavior in the foreseeable future. However, persons close to you may be aware of the existence of a problem. If you are in treatment, it is normally only as a result of coercion by someone in your environment (e.g., family insistence, employer requirement, or legal mandate). The idea of change is not seriously considered.

CONTEMPLATION

You are becoming aware that a problem exists; you may be considering behavior change but have not made a commitment, such as setting a goal. You often are weighing the pros and cons of the compulsive behavior, and may be either over-estimating the pros or under-estimating the cons. Perhaps you've read a great deal on the subject. Yet none of this information seems to have made any difference. The habit endures.

It is very easy to miss out on a brief window of opportunity, a moment in which you are saying to yourself, "I've had it! No more of this! I'm doing something about this right now!" You are very vulnerable to old influences at this time, both external pressures and convincing data from within. It is imperative to tip the scale of ambivalence in order to move from contemplation to determination/preparation and action.

PREPARATION

In this stage, you have the intention to change but have not established a specific goal. In the Preparation stage, you often reduce compulsive behavior, but not enough to have a qualitative effect on your life.

This is a transition period between shifting the balance in favor of change and getting things moving in that direction. You may have fleeting moments of determination that swiftly vanish when all of the horrors involved come back into awareness. Determination will lead directly into action if you have thoroughly considered all aspects of your compulsive problem realistically, if you have begun to modify expectancies and have established a goal what is conducive to your individual needs and values. Your goals must be consistent with your capabilities, your values, your needs.

ACTION

Simply expressing a desire to change is not the same thing as action, and until you have started a clear program, you should be considered to be in the Preparation Stage. It is important to remember that "paying lip service" to the problem is not the same as actively working to change the problem. In the Action Stage, you are actively taking steps to reduce your Compulsive Hoarding. You are making changes in your behavior and are altering your environment in order to attain your goals.

MAINTENANCE

In this stage, you strive to consolidate the gains made during the Action stage, in particular to prevent relapse in your compulsive behavior. Prochaska and colleagues define maintenance as being beyond six months of having successfully attained a desired change in order to be considered in the Maintenance versus the Action stage.

For those of you who are in the pre-contemplation, contemplation or perhaps even the preparation stages, continue to read everything you can get your hands on about compulsive hoarding. The best place to start is the OCF Hoarding Webpage.

It may take some time to educate yourself about the disorder, and to deal with your ambivalent feelings about change and all your "stuff". It will take as long as it takes to explore the pros and cons of change.

It may take some time, but this is an integral part of the process of change.

The above information came from a private online support group for Hoarders called H-C. This nformation was adapted for H-C from: James Claiborn Ph.D., Cherry Pedrick R.N., <u>The Habit Change Workbook.</u>

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Compulsive Hoarding & OCD-Two Distinct Disorders?

Input from Researchers-Letters to editor/American Journal of Psychiatry American Journal of Psychiatry, 164:1435, September 2007- doi: 10.1176/appi.ajp.2007.07030425

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Letter to the Editor »Compulsive Hoarding and OCD: Two Distinct Disorders?

DANIEL S. VAN GROOTHEEST, M.D. and DANIELLE C. CATH, M.D., Ph.D. Amsterdam, the Netherlands

To The Editor: The editorial by Sanjaya Saxena, M.D.» (1), in the March 2007 issue of the Journal, implicates that there is enough research-based evidence to justify that compulsive hoarding constitutes a discrete entity, apart from obsessive-compulsive disorder (OCD) as such, to be placed separately in the future DSM-V classification system. The important article by Jack Samuels, Ph.D., et al. (2), also published in the March 2007 issue of the Journal, contains several results that cast doubts on this conclusion.

First, all but six of the hoarding individuals in the cohort assessed by Dr. Samuels et al. (2) had additional obsessions and compulsions, especially symmetry and somatic obsessions, as well as repeating, counting, and ordering compulsions (3), indicating substantial symptom overlap with other perhaps intuitively more "typical" OCD symptom dimensions.

We therefore do not agree with the authors that many of the hoarders do not have other OCD symptoms. Second, as also mentioned by Samuels et al. (2), hoarding in itself seems to be heterogeneous. In our opinion, the "hoarding" criterion of obsessive- compulsive personality disorder, characterized by thrift, differs from the three core symptoms of clinically significant compulsive hoarding. Moreover, within groups of patients with significant compulsive hoarding, we observe clinical heterogeneity.

Furthermore, hoarding can arise as a secondary condition from other disorders, such as schizophrenia, dementia, and Prader-Willi syndrome. Third, the linkage study conducted by Samuels et al. (2) was done so on the presence of any hoarding symptom in a potentially heterogeneous group of hoarding individuals instead of a group with clinically significant compulsive hoarding.

We therefore feel that their results do not add evidence with respect to the hypothesis that compulsive hoarding is an etiologically discrete phenotype from OCD.

In addition, Samuels et al. (2) noted that they found linkage peaks at a chromosome different from that reported in a previous linkage study on hoarding. Replication of these findings is needed before we can conclude that there is a special susceptibility locus for hoarding.

In summary, the points mentioned in the article by Samuels et al. (2) suggest that evidence for hoarding as a distinctive syndrome is not very sound, since hoarding seems both phenomenologically and genetically heterogeneous, possibly with subtypes related and subtypes unrelated to OCD. Therefore, much more research on hoarding is needed before implications for a new diagnostic classification can be made.

American Journal of Psychiatry- 164:1436, September 2007, doi: 10.1176/appi.ajp.2007.07030425r2, © 2007 American Psychiatric Association, Letter to the Editor

<u>Dr. Samuels Replies»</u> JACK SAMUELS, Ph.D., Baltimore, Md.

To The Editor:

We agree with Drs. Grootheest and Cath that hoarding behavior may be

heterogeneous, "possibly with subtypes related and subtypes unrelated to OCD." Indeed, on page 498 of our article, we noted that hoarding behavior can occur in conditions other than OCD, and we wrote that "we suspect that hoarding behavior itself is heterogeneous, and that the etiology of hoarding behavior is different in various syndromes."

However, as noted by Dr. Saxena, all of the families in our cohort were recruited because they had two or more relatives affected with OCD, and thus OCD was over-represented in the hoarding participants. On page 497, we suggested that Zhang et al. (1) may have found different linkage peaks for hoarding in their study because they selected families with multiple siblings affected with Tourette's syndrome, not OCD (1).

Certainly, more work is needed in order to refine the phenotypic definition of hoarding, including the clinical features outlined by Dr. Saxena.

As pointed out by Drs. Van Grootheest and Cath, there was a range of severity in the hoarding individuals in our cohort, but the majority (68%) reported spending at least 1 hour per day and/or experiencing moderate, severe, or extreme distress that was frequent and disturbing during the worst period of their hoarding behavior.

We stand by our conclusion that the findings of our study suggest that a region on chromosome 14 is linked to compulsive hoarding behavior in these OCD families. We hypothesize that there is a genetic variant in this region that increases the risk of hoarding behavior in individuals who are susceptible to OCD. Additional genetic studies are required to replicate these findings and to characterize the genetic variant that may be involved.

»DSM-V Planning & Research Website

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Animal Hoarding

»Animal Hoarding News Only

»The Hoarding of Animals Research Consortium (HARC)

»News from HARC

»Humane Society of United States

»Animal Sheltering

<u>»Interventions</u>

»Public Policy

»Resource Manual

»More News

»New Report

»More Animal Hoarding articles

»Fact Sheet from wildlifeprotection.net

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Links to other sites to learn from

Anxiety Disorders Center, The Institute for Living

Bio-Behavioral Institute

del.icio.us list (bookmarking network) of Compulsive Hoarding sites

hoarders.org

Messies Anonymous

Obsessive Compulsive Foundation Hoarding Website

OCD-Action, United Kingdom

MHA San Francisco, Hoarding pages

San Francisco Bay Internet Guide to Compulsive Hoarding

Squalor Survivors

Understanding Obsessive Compulsive Hoarding Disorder

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Additional:

»Anthropomorphism.org Understanding Hoarding-In The News

"Along with difficulties in throwing things away, compulsive hoarders have severe difficulties with making decisions, perfectionism, and avoiding tasks. People with compulsive hoarding syndrome do not like to make mistakes. In order to prevent making a mistake, they will avoid making or postpone decisions."-Karron Maidment» RN, M.A., Behavior Therapist-UCLA OCD, Intensive Treatment Program

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- 1: <u>Compulsive Hoarding Syndrome: An Introduction</u>, Karron Maidment RN, M.A., Program Coordinator/Behavior Therapist, UCLA OCD Intensive Treatment Program.
- 2: <u>Problems in Treating Compulsive Hoarding</u>: Karron Maidment RN, M.A., Program Coordinator/Behavior Therapist, UCLA OCD Intensive Treatment Program.
- 3: <u>Overcoming Compulsive Hoarding,</u> Chapter 1, By: Fugen Neziroglu, Jerome Bubrick, Jose A. Yaryura-Tobias
- 4: <u>Hoarding: Where Does It Belong?</u>, James Clairborn, Ph.D., Northeast Occupational Exchange, Portland, Maine.
- 5: Mathews CA, Nievergelt CM, Azzam A, Garrido H, Chavira DA, Wessel J, Bagnarello M, Reus VI, Schork NJ: Heritability and clinical features of multigenerational families with obsessive-compulsive disorder and hoarding. Am J Med Genet B Neuropsychiatr Genet 2007; 144:174–182 [Medline]
- 6: Cullen B, Brown CH, Riddle MA, Grados M, Bienvenu OJ, Hoehn-Saric R, Shugart YY, Liang KY, Samuels J, Nestadt G: Factor analysis of the Yale-Brown Obsessive Compulsive Scale in a family study of obsessive-compulsive disorder. Depress Anxiety 2007; 24:130–138 [CrossRef][Medline]
- 7: The Neurobiology and Medication Treatment of Compulsive Hoarding, Sanjaya Saxena, M.D.

Information published by the federal government's $\underline{\text{National Institute of Mental Health (NIMH)}}$ is available at no cost by writing:

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