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New England Hoarding Consortium's

# Hoarding *newsletter*

SPRING 2009

*Compiled by Stephanie Chervenak, B.A. & Rachel Novosel, M. A.*

## Welcome!

Once again, we are delighted to send you the newsletter from the New England Hoarding Consortium (NEHC). The NEHC is comprised of a group of clinicians and researchers at the Institute of Living in Hartford, CT, Smith College in Northampton, MA, and Boston University in Boston, MA.

As always, this newsletter will provide you with the latest information coming out of our research studies on compulsive hoarding, recently-published findings from other researchers, and our responses to some of the important questions people ask on our web site ([www.compulsivehoarding.org](http://www.compulsivehoarding.org)). We also feature essays on important clinical and research topics written by members of our staff. We are also very happy to include an article written by Dr. Lawrence Haber, Director of the Family Resource Center at the Institute of Living. Dr. Haber specializes in working with family members of people who are struggling with psychiatric and behavioral issues.

If you received this newsletter directly from us, that means you are on our mailing list and we will automatically send you future issues. If for some reason you do not want to be on our mailing list, please email us at [adcresearch@harthosp.org](mailto:adcresearch@harthosp.org), call us at 860-545-7039, or send me a letter at 200 Retreat Avenue, Hartford, CT 06106. If you received this newsletter from someone else, and would like to be added to our mailing list, please let us know using the same contact information or log on to [www.compulsivehoarding.org](http://www.compulsivehoarding.org). Because we do not charge for the newsletter, we are only able to send it by e-mail.

Our sincere hope is that you will find this newsletter helpful, and that the information will give you new insights and ideas for working on the problem of compulsive hoarding.

Best Wishes,



David Tolin, Ph.D.



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## MEET THE RESEARCH TEAM

### **RANDY O. FROST, PH.D.**



Dr. Frost is the Harold Edward and Elsa Siipola Israel Professor of Psychology at Smith College. He is an internationally known expert on obsessive-compulsive disorder and compulsive hoarding, as well as the pathology of perfectionism. He has published over 100 scientific articles and book chapters on these topics. His work has been funded by the National Institute of Mental Health and the Obsessive Compulsive Foundation. He is coauthor with Gail Steketee of *Compulsive Hoarding and Acquiring: Therapist Guide* and an accompanying workbook published by Oxford University Press in 2007. Together with Dr. Steketee and Dr. David Tolin, he is co-author of *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding*, also published by Oxford in 2007. His newest book, *Stuff: Compulsive Hoarding and the Meaning of Things*, also co-authored by Dr. Steketee, is due out next spring and will be published by Houghton Mifflin Harcourt. His research has been featured on a variety of television and radio news shows including 20/20 Downtown, Good Morning America, Dateline, National Public Radio (general news as well as the award winning program The Infinite Mind), BBC News, and the Canadian Broadcasting Company's The Nature of Things. He has also consulted with various Hoarding Task Forces including those in New York City; Ottawa, Canada; and Northampton, MA, and has given hundreds of lectures and workshops on the topic across the country.

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### **GAIL STEKETEE, PH.D.**



Dr. Steketee, Professor and currently Interim Dean at the Boston University School of Social Work, has conducted multiple research studies of OCD and its spectrum conditions, including body dysmorphic disorder and the nature and treatment of compulsive hoarding. With colleagues Randy Frost, PhD and David Tolin, PhD, her recent NIMH grant developed a specialized cognitive and behavioral treatment for this syndrome. Additional research interests include the psychopathology of compulsive hoarding, and treatment of obsessive compulsive disorder and body dysmorphic disorder. She has published over 150 articles, chapters and books on OCD and related disorders. Her recent books include *Compulsive Hoarding and Acquiring: Therapist Guide* (Steketee & Frost) and *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding* (Tolin, Frost & Steketee), both by Oxford University Press in 2007, as well as *Cognitive Approaches to Obsessive Compulsive Disorder* (Wilhelm & Steketee, New Harbinger, 2006).

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### **DAVID F. TOLIN, PH.D.**



Dr. Tolin is the founder and Director of the Anxiety Disorders Center at The Institute of Living. The author of over 80 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 neuroimaging to study hoarding as well as a study of neuropsychological functioning in people who hoard. Dr. Tolin has been a recurrent guest, discussing compulsive hoarding, on Good Morning America, the Today Show, ABC Medical Mysteries, and The Oprah Winfrey Show.



## NEHC UPDATE



As usual, we want to take the opportunity to share with you the results of our ongoing research. If you participated in our research, we offer our sincere thanks—you are helping us learn about hoarding, and, in turn, helping us to help others. If you haven't participated yet (or have participated in previous research and would like to do so again), you'll find information in this newsletter about how to join us.

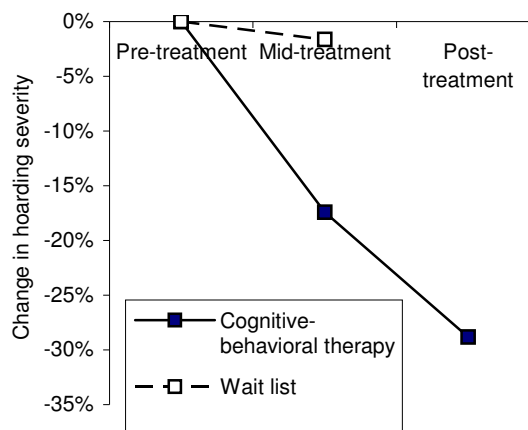
We are currently in the final stages of our study "Psychopathology of Compulsive Hoarding" (R. Frost & G. Steketee, principal investigators), also sponsored by NIMH. Results of this study are expected to help us more fully understand the symptoms of hoarding, as well as the characteristics of people with hoarding problems. You may recall from previous editions of this newsletter that we were finding that the rate of obsessive-compulsive disorder (OCD) was not nearly as high among people who hoard as one might anticipate (17%), leading us to question how strongly hoarding and OCD are related. Conversely, over half (58%) of people with compulsive hoarding met criteria for Major Depressive Disorder. A recent analysis from that study shows us that 20% of people with hoarding problems, compared to 4% of people with OCD and 3% of people selected from the community, meet current (adulthood) criteria for the inattentive subtype of Attention-Deficit/Hyperactivity Disorder (ADHD).

Work on our study "Neuropsychological Functioning in Compulsive Hoarding" (D. Tolin, principal investigator) continues. In this study, people with compulsive hoarding, people with OCD, and people selected from the community

are asked to complete a battery of tests of cognitive functioning. Overall, people with and without hoarding perform similarly on most of these tests. However, people with hoarding problems are showing diminished ability to sustain attention on a task called the Continuous Performance Test. We suspect that problems of attention might be part of the decision-making difficulties people frequently report to us.

We also recently completed work on our study "Treatment of Compulsive Hoarding" (G. Steketee, principal investigator), sponsored by the National Institute of Mental Health (NIMH). In this study, people with hoarding problems were randomly assigned to 9-12 months of individual cognitive-behavioral therapy, or to a 12-week wait list (treatment was provided after 12 weeks of waiting). People who received cognitive-behavioral therapy improved on all

Figure 1. Changes in hoarding severity for patients receiving cognitive-behavioral therapy or wait list.







measures, with symptom improvements ranging from 24-37%. Figure 1 shows changes on the Saving Inventory-Revised, a measure of hoarding severity, for people receiving cognitive-behavioral therapy or wait list. Clinicians rated 69% of people receiving cognitive-behavioral therapy as either "much improved" or "very much improved" at the end of treatment.

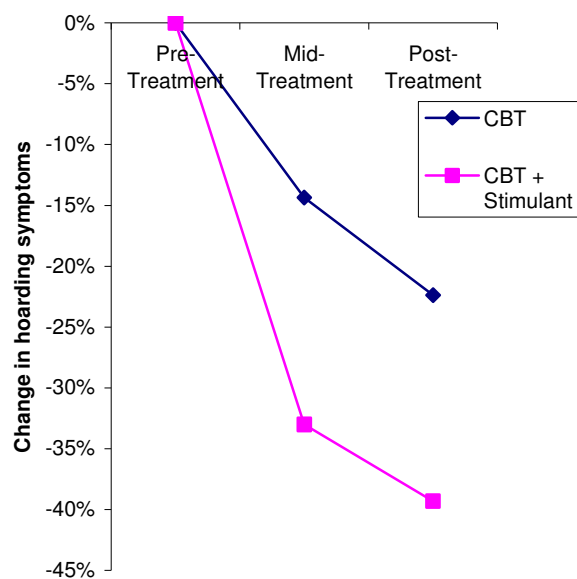
While we were completing our research on individual cognitive-behavioral therapy, we also examined the effectiveness of the same treatment delivered in a group format (J. Muroff, principal investigator). Group therapy is usually considered a good alternative to individual therapy because it is more affordable and easier to implement in many clinical settings. Four cognitive-behavioral therapy groups met for 16-20 weekly sessions, with 5-8 patients per group. Each group member also received 2-3 individual home visits by the therapist. Results showed significant decreases in overall hoarding severity, as measured by the Saving Inventory-Revised, although group therapy may have been somewhat less effective than individual therapy (a 14.25 point reduction on the Saving Inventory-Revised in group therapy, compared to an 18.7 point reduction in individual therapy). Nevertheless, we think that the reduced cost and easier dissemination of group therapy makes it a viable option and we plan to refine and study this treatment further.

As we were conducting the therapy groups, we made an observation that seemed potentially important. Recall from the previous discussion that people who hoard show a high rate of ADHD symptoms, and seem to have problems on tests of attention. We wondered, therefore, whether people might benefit from taking stimulant medications, such as those used for ADHD, in combination with cognitive-behavioral therapy. Sure enough, when we

divided 15 group members according to what kind of medications they were taking, we found that people taking stimulant medications responded substantially better to cognitive-behavioral therapy than did people not taking these medications (see Figure 2). This is a very small, uncontrolled study, so we want to make sure to emphasize that the results should be interpreted very carefully and that this is not sufficient evidence to justify changing your medications. However, we find it interesting and encouraging, and plan to study this topic further.

In addition to these treatment studies, we are exploring the efficacy of self-help strategies (R. Frost, principal investigator) using our book *Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding* (Tolin, Frost, & Steketee, Oxford University Press). Not everyone is willing or capable of entering into a treatment program, and self-help strategies may be a useful first step in the process of conquering a

Figure 2. Changes in hoarding severity for patients receiving cognitive-behavioral therapy with or without stimulant medications.





hoarding problem. We have developed a facilitated self-help group protocol in which nonprofessionals (i.e., college students) who have some knowledge of hoarding facilitate 13 weekly self-help meetings. Each week focuses on 1 or 2 chapters of *Buried in Treasures*. Facilitators take care of the organizational details such as time and location. They also provide homework forms, help with the set up of behavioral experiments, and keep the discussion on track. The outcomes from our initial study were impressive with significant reductions in clutter, difficulty discarding, and excessive acquisition on the Saving Inventory-Revised, as well as significant reductions in Clutter Image Ratings of rooms in the home. If you live within driving distance of Northampton, Massachusetts, please call (413) 585-3986 to see about participating.

Work is also ongoing in our NIMH-funded study "Neural Mechanisms of Compulsive Hoarding" (D. Tolin, principal investigator). In this study, people with and without compulsive hoarding are put into a functional magnetic resonance imaging (fMRI) scanner so that we can observe their brain activity. While in the scanner, participants are asked to make the decision to discard personal possessions. The experimenter holds up pieces of the person's "junk" mail, and the person is asked to indicate, by pressing a button, whether or not to discard it. If the participant opts to discard the item, it is placed into a shredder. In a previous version of this study, we found that for people with compulsive hoarding, decisions to discard personal possessions activated brain regions associated with processing punishing or unpleasant events. Refusals to discard personal possessions activated regions associated with

categorizing, as well as intense emotional processing. These results may provide insight into why people who hoard have such great difficulty discarding items: Decisions to discard may be experienced as punishing, and thus be avoided in the future. Unsuccessful decisions to discard may result from the inability to properly classify the item and thus be able to take action. This study will continue for the next year. If you live within driving distance of Hartford, please call (860) 545-7685 to participate.

We continue to receive positive feedback about our reference books on hoarding. *Buried in Treasures: Help for Compulsive Acquiring, Saving and Hoarding* (Tolin, Frost, & Steketee, Oxford University Press) is a self-help manual designed for people who hoard, family members of people who hoard, and professionals (professional organizers, social service workers, attorneys, etc.) who work with people who hoard. *Compulsive Hoarding and Acquiring: Therapist Guide* (Frost & Steketee, Oxford University Press) is a manual for mental health therapists who want to use cognitive-behavioral therapy for people with hoarding problems. *Compulsive Hoarding and Acquiring: Workbook* (Frost & Steketee, Oxford University Press) is a client manual that is designed to fit with the therapist manual. The book is recommended for people who are seeing a mental health therapist who is using the therapist manual. All three of these books are available at [www.oup.com](http://www.oup.com) or at your local bookstore or online retailer; you will also find an advertisement for the books in this issue of the *NEHC Newsletter*. We hope you find them helpful!



## NOTES FROM THE RESEARCH TEAM

At first glance for many, the main struggle presented by compulsive hoarding is the clutter. Overflowing a person's drawers, closets and storage spaces, limiting living space and making certain aspects of the home inaccessible and non-functioning, clutter is surely the main culprit. However, as many who face compulsive hoarding, as well as their loved ones know, clutter problems almost always occur in conjunction with difficulty throwing items away and for some, problems with collecting or buying more items than one needs (acquisition). Researchers and therapists believe that difficulty with discarding and problems with acquisition play an important role as behaviors which often create and influence clutter.

In working with individuals dealing with compulsive hoarding, therapists have found that addressing the discarding and acquisition behaviors are a crucial part of treatment. Recently, researchers at Boston University and Institute of Living in Hartford, CT have been further investigating the processes of discarding and acquisition in those with compulsive hoarding. They have done so through a series of experimental tasks which mimic challenge opportunities presented in treatment. These tasks are designed to elicit thoughts and feelings associated with discarding and acquisition, in order to more fully understand the phenomenon and further inform future treatments.

In the discarding task, carried out in the individual's home, the participant is asked to select a personal item with little to no

sentimental or financial value and make a decision about whether to keep or throw away the item. Before making the decision, participants are assigned to either list their thoughts about the item or answer a series of questions about the possession on tape. If the decision is made to discard, participant's distress levels about discarding are then rated every 5 minutes for 15 minutes after listening to their tape three times. Thus far, researchers have learned a great deal about the challenges present in discarding and the benefits of performing the task for those with compulsive hoarding. In the process of selecting an item and anticipating discarding, participants are engaging in an imaginal exposure. They have often expressed feelings of sadness, anxiety, guilt and anger and thoughts concerning doubt, safety, responsibility and attachment related to items. Numerous participants have found that hearing themselves talk about their thoughts on tape has unexpectedly been one of the hardest parts. For many, it is the first time they may have heard their thoughts voiced aloud and frustration, shame, embarrassment and anger might accompany this. However, it has also often resulted in sense of relief and validation at the same time. It has not been uncommon for individuals to become very emotional. For those participating, most have been surprised to experience the intensity of emotion around discarding reduce as time goes on. The task allows them to try out one of their worst fears and turn to face it head on. For many individuals, the chance to explore their feelings and the thoughts surrounding a possession has been powerful experience both cognitively and emotionally.



The acquisition task is similar to the discarding task, differing in that it is held in a place of acquisition as opposed to the home. The place of acquisition varies across individuals, ranging from a store, to the side of a road, to the internet or home shopping network. So far, investigation into the acquisition task has greatly informed researchers on the process. For some, collecting or buying things is described as being in “another place” or another “zone” which feels “impulsive” or “out of control”, while for others it feels “calculated” and “controlled”. The type of items acquired significantly range from effects such as glass vases to paper pamphlets. Despite differences, in place, process and type of items acquired, participants have expressed similar thoughts and feelings surrounding the acquisition. Thoughts include doubt about having enough items, responsibility to acquire for others, uniqueness or appreciation for the aesthetics

of an item and future planning for use of items. A mix of feelings often surrounds acquisition such as pleasure, anxiety, anger, sadness. Participants have found it helpful to stop for a moment and question their thoughts and feelings surrounding the acquisition instead of following through on it automatically. It is clear from the experimental task that acquisition can be major contributor to clutter and is helpful to address in treatment.

Overall, both of the challenge tasks have been a learning experience for participants and researchers alike. It has been clear that these processes can be similar and yet unique in a number of ways for individuals with compulsive hoarding. It also has become apparent that the two behaviors of difficulty with discarding and excessive acquisition are key features of compulsive hoarding and benefit from being addressed in conjunction to clutter itself.

*Written and submitted by  
Jessica Rasmussen, M. A.  
Clinical Fellow  
Boston University*

## **Be Part of the Research**

We will soon be starting our next internet-based study about compulsive hoarding. This study will be open to individuals with compulsive hoarding, as well as their family members and treatment providers. If you are interested in participating in our internet study, be sure you're on our mailing list by sending us an email at [adcresearch@harthosp.org](mailto:adcresearch@harthosp.org).



# Compulsive Hoarding Titles from the Research Team

## AS SEEN ON OPRAH

### Buried in Treasures

Help for Compulsive Acquiring, Saving, and Hoarding

DAVID F. TOLIN, RANDY O. FROST, AND GAIL STEKETEE

*Buried in Treasures* outlines a scientifically-based and effective program for helping compulsive hoarders dig their way out of the clutter and chaos of their homes.

Discover the reasons for your problems with acquiring, saving, and hoarding, and learn new ways of thinking about your possessions so you can accurately identify those things you really need and those you can do without. Learn to recognize the “bad guys” that maintain your hoarding behavior and meet the “good guys” who will motivate you and put you on the path to change.

#### Features of this book include:

- Self-assessments to determine the severity of the problem
- Tips and tools for organizing your possessions and filing your paperwork
- Strategies for changing unhelpful beliefs about your possessions
- Behavioral experiments to reduce your fear of anxiety and fear of discarding

**“I would recommend this book to treatment providers, professional organizers and the compulsive hoarder. This book, if used properly, will guide the reader to clutter-free living!”**—Patricia B. Perkins, JD, Executive Director, OC Foundation, Inc.

**“The world’s leading experts on compulsive acquiring, hoarding and saving have presented their proven, step-by-step treatment in a practical, easy-to-understand format that will be useful to anyone who hoards, as well as any professional who treats this problem. If you are looking for ways to clear your clutter, you need to read this book now!”**—Martin M. Antony, Ph.D., ABPP, Professor, Department of Psychology, Ryerson University, Author, *When Perfect Isn’t Good Enough*

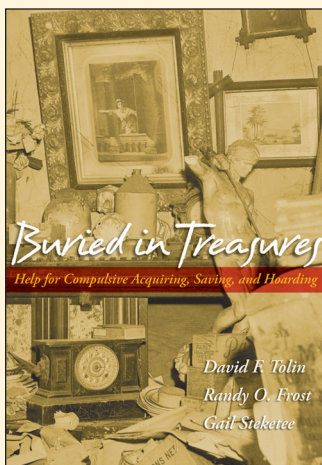
2007 152 pp.

978-0-19-530058-1 paper \$16.95

**DAVID F. TOLIN, PH.D.** is the founder and Director of the Anxiety Disorders Center at The Institute of Living. He received his Ph.D. from the University of Arkansas, and completed a predoctoral internship at Tufts University School of Medicine/VA Medical Center, Boston. Dr. Tolin is the author of over 70 journal articles and book chapters, and over 120 research presentations to national and international organizations.

**GAIL STEKETEE, PH.D.** is Professor at the Boston University School of Social Work. Her recent research, funded by the National Institute of Mental Health, focuses on diagnostic and personality aspects of compulsive hoarding and tests a specialized cognitive and behavioral treatment for this condition. She has published over 150 journal articles, chapters and books on OCD and related disorders.

**RANDY O. FROST, PH.D.** is the Harold Edward and Elsa Siipola Israel Professor of Psychology at Smith College. He has published over 100 scientific articles and book chapters on obsessive-compulsive disorder and compulsive hoarding and is co-editor of the Obsessive Compulsive Foundation (OCF) website on hoarding. His work on compulsive hoarding is funded by grants from the National Institute of Mental Health.



### Compulsive Hoarding and Acquiring

Therapist Guide & Workbook

GAIL STEKETEE AND RANDY O. FROST

*Compulsive Hoarding and Acquiring, Therapist Guide and Workbook* are the first books to outline an empirically-based and proven effective treatment for compulsive hoarding and excessive acquiring. Based on the principles of cognitive-behavioral therapy, the treatment program described aims to provide clinicians with the tools they need to help their clients manage their problems with clutter and organization. Elderly clients, as well as those with compulsive disorders have shown to be positively affected by participating in this program. It teaches individuals how to recognize errors in thinking and uses both imagined and real exposures to teach them the skills they need to manage their problem. Home visits by the clinician are also a part of the treatment, as well as consultations with a professional organizer if necessary. Homework exercises include monitoring progress, developing an organization plan and filing system, and sorting and organizing items room-by-room.

**“The treatment program presented in this therapist guide and accompanying workbook represents the first attempt to treat compulsive hoarding with any systematic evidence of efficacy. This program, originated by the widely acknowledged experts in the world in this area, leads to substantial improvement in most patients. In the most recent study, a group receiving treatment achieved close to a 50% reduction in hoarding systems, far superior to the group not receiving treatment. While we have much to learn about the nature in treatment of compulsive hoarding, this program represents the best hope for this intractable condition at the present time.”**—David H. Barlow, Editor-in-Chief, *Treatments That Work*<sup>TM</sup>, Boston, MA

#### Therapist Guide

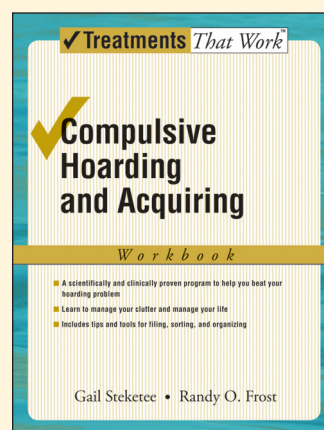
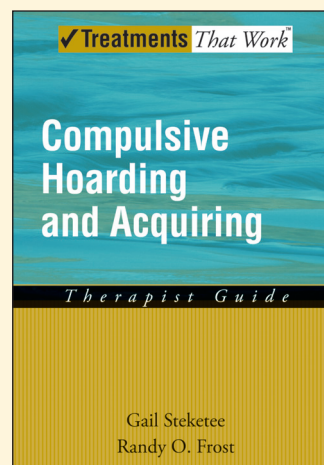
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#### Workbook

2007 160 pp.

978-0-19-531055-9 paper \$24.95



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## QUESTIONS & ANSWERS

**Q: "My daughter has been a hoarder for a long time, but we only recently discovered her hoarding behavior. I live far away and have had difficulty finding an appropriate therapist, group, or support services in her area. Being so far away, how do I help her find these services in her own town?"**

- Judy, North Carolina

**A.** To find referrals for someone who has a hoarding problem, you can contact the OC Foundation at [www.ocfoundation.org](http://www.ocfoundation.org). Visit the section on hoarding to learn more about this problem, including information about support groups. You can also find a list of doctors by geographic area who treat OCD; you will need to call the treatment provider(s) to determine whether the person is also trained and experienced in treating hoarding. Another option is to contact Dr. Christiana Bratiotis at Boston University ([cbrat@bu.edu](mailto:cbrat@bu.edu)) where we maintain a referral list of clinicians around the country who have indicated their interest in treating hoarding. We cannot promise that we will have someone in your family member's geographic area as treatment providers for hoarding are still somewhat scarce, though this is improving rapidly. Please note that we do not vouch for the quality of care provided. In addition to these referral sources, consider contacting the local department of aging if your family member is age 60 or older. If the situation is extreme and you are worried about risk or danger to the person or the home, you can also contact the local organization that provides Adult Protective Services and/or Child/Family Protective Services to find assistance.

- Dr. Gail Steketee

**Q: "My mother is a hoarder, and I have been highly motivated to keep clutter out of my own home. My son, however, is not as motivated and appears to have hoarding tendencies. Is it possible that early intervention treatment could help him avoid trouble with hoarding behaviors in the future?"**

- Anonymous, Mississippi

**A:** One of the things we are learning from our research is that for most people with compulsive hoarding, the problem starts very early. We recently surveyed 751 people with hoarding problems, and found that the majority reported an onset of hoarding behaviors prior to age 20. We don't yet know how many young people stop hoarding on their own; however, it seems reasonable to conclude, at a minimum, that the roots of adult hoarding are frequently found in childhood or adolescence.

Would early intervention help? Quite possibly. So far, our treatment research has just focused on adults who have been hoarding for a long time, and to my knowledge, no one has systematically studied the effects of treatment on young people who hoard. But we have ample evidence from other psychiatric conditions, such as OCD, that kids and adults respond fairly similarly to various treatments. We also know from studies of conditions such as depression that a little bit of preventative treatment for young people who seem to be at risk can reduce the likelihood that the symptoms will worsen over time.

One tricky issue raised by your question concerns your son's level of motivation. Time and again, we find that you just can't force someone into

*Continued on next page*



treatment and expect it to work. So you may need to be extra patient with him. Start by having a frank discussion of your concerns, but be sure not to let it turn into an argument. It might be that you have to "plant the seed" many times before he starts to acknowledge the problem, agrees that he needs to do something about it, and decides to allow others to help him.

- Dr. David Tolin

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**Q: "What distinguishes true hoarding tendencies from tendencies toward laziness? Would it be realistic to think that someone could suffer from both?"**

- Robin

**A:** Although a principle feature of hoarding is the failure to discard or get rid of possessions, it is not the same thing as simply being too lazy to do so. For people who hoard, difficulty discarding possessions is associated with beliefs about and attachments to objects. Those beliefs and attachments have to do with the objects' potential usefulness, importance, or emotional significance. People with hoarding problems can't tolerate the prospect of losing important information or losing something that is emotionally meaningful. Attempts to do so produce distress and indecision. Saving things reduces or avoids altogether these unpleasant experiences.

Laziness, on the other hand, implies a lack of motivation. People who can easily discard unneeded items sometimes have a hard time seeing how difficult it is for people who do to get rid of or organize things. When they see a room filled with things they could easily discard, they imagine the problem is one of motivation (i.e., laziness) rather than attachment. For instance, the first thought of someone without a hoarding

problem upon seeing a room filled with stuff is often "in just a few hours, I could make a significant dent in the clutter in this room". Since there is little recognition of how difficult this would be for someone with a hoarding problem, laziness is an easy explanation.

There are a couple of circumstances in which motivation to get rid of things is low, and can look like laziness. For instance, sometimes people with hoarding problems know they want to get rid of things, but before they can, they must extract anything of importance from them. Often this material is trash or clearly useless objects. This form of hoarding involves an obsession over being certain that nothing is being lost. To create that sense of certainty, the object must be thoroughly checked. However, the effort this requires is so great and the process so time-consuming, that the amount discarded in this way could never keep up with the material flowing into the home. In these circumstances, people with hoarding problems sometimes give up and no longer try. This can look like simply laziness. In addition, people with hoarding problems often suffer from depression as well. Motivation to do anything is severely compromised when someone is depressed. Neither of these circumstances reflect simple laziness, however.

It may be possible for someone to have hoarding tendencies and be lazy as well, but the two are not synonymous.

- Dr. Randy Frost

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**◆ If you have a question regarding compulsive hoarding that you would like answered, please contact us via email at [adcresearch@harthosp.org](mailto:adcresearch@harthosp.org).**



## SUMMARY OF AVAILABLE SERVICES AT THE INSTITUTE OF LIVING

At the Institute of Living we currently have available a number of different services for those with compulsive hoarding and their families. Services range from diagnostic evaluations, to family consultations, and group therapies. All services are provided by trained mental health professionals. A list and description of some of the services offered is included below. Additional information can be obtained by calling the Anxiety Disorders Center at (860) 545-7685.

<b><i>Diagnostic Evaluation</i></b>	The evaluation is a 3 hour long in-person clinical individual assessment which looks at symptoms related to compulsive hoarding, as well as issues which may not directly impact the clutter, but may affect diagnosis and treatment.
<b><i>Group Therapy</i></b>	Group therapy is an additional treatment option, and consists of groups of at least six people within the area. Group members no longer travel to homes. Clients can request an individual session (at additional cost) to do a home visit.
<b><i>In-Person Family Consultation</i></b>	Office-based consultations can be arranged for family members in order to better familiarize family with compulsive hoarding and let them know what they can do to help. Sessions typically last 45-50 minutes.
<b><i>Telephone Initial Evaluation</i></b>	Individual initial assessment is also available over the phone and lasts about 2 hours.
<b><i>Telephone Family Consultation</i></b>	Family consultations also have the option of being carried out over the phone. These sessions also last approximately 45-50 minutes.
<b><i>In-Home Consultation</i></b>	Qualified health professionals are also available to attend home consultations and treatment visits. Sessions last 90 minutes and vary in rate based on location. Special 2-day intensive consultation and treatment packages can be arranged for people who live a long distance from our clinic.





## SUMMARY OF AVAILABLE SERVICES AT BOSTON UNIVERSITY SCHOOL OF SOCIAL WORK

The Boston University School of Social Work provides services for those with compulsive hoarding and their families who are interested in participating in our research projects. We are not a full service clinic. Services include initial telephone screening and referral, diagnostic assessment, group treatment, and support groups.

A description of the services offered is provided below. Additional information can be obtained by calling the Boston University Hoarding Project at the School of Social Work at (617) 353-0815.

<b><i>Initial Telephone Screening and Referral</i></b>	Initial telephone assessment of hoarding problems is available by phone to determine eligibility for research opportunities, services and referral.
<b><i>Diagnostic Assessment</i></b>	The evaluation is a 3-4 hour in-person clinical individual assessment of symptoms related to compulsive hoarding or OCD, as well as other problems.
<b><i>Group Treatment</i></b>	Group therapy may be available for six or more people with hoarding who live within 40 minutes of Boston so group leaders can visit clients' homes periodically.
<b><i>Support Groups</i></b>	Weekly support group meetings are open to people with hoarding who have already completed individual and group cognitive and behavioral treatment but want continuing support to make further progress and maintain their gains. These groups take place in Kenmore Square at the Center for Anxiety and Related Disorders.



## *Helping Family Members Who Hoard: I Am Not The One That's Ill*

You love someone. They are turning their life into a shambles; creating a disaster...putting themselves at risk... making horrible choices... etc., etc. You desperately want to help them, but they politely or not so politely refuse your help. They do not think that they have a problem. This is a problem that families face whether we are talking about Hoarding, Schizophrenia, an Eating Disorder, or many other mental illnesses.

I have been asked many times by families how to get help for somebody who needs help but is unwilling or unable to accept it. This is a very difficult problem and unfortunately the answer is not what people want to hear. Connecticut, like most states, places a premium on individual rights. A person can be treated without their consent only if they are dangerous to self or others or so gravely disabled that they are at risk. These laws are interpreted very strictly so that somebody can be quite ill but not meet the criteria for gravely disabled. If somebody meets the criteria they can be committed to a hospital for care. Every part of the state has a mobile crisis team which can come out and evaluate somebody where they are to see if they meet the criteria. The police can also be called and if they think somebody is at risk, they can bring them to a hospital for an evaluation. Connecticut has no outpatient commitment laws, meaning that once somebody is stable they will be released from the hospital and can once again refuse help. The average stay at a hospital is less than 7 days. Thus, this is not a solution.

Concerned family members are not without power. The love and caring that exists might convince somebody to do it for you. Whether it is nagging, cajoling, or outright bribery; families have gotten their loved ones the help that they need.

If that doesn't work, you still have things that you can do. You are probably providing a lot of support for the person who is ill. This support may be in

the form of money, or transportation, or they may be living with you. For example you might tell someone that getting treatment is the rent that they have to pay you for living here.

If that doesn't work, there are other things that you might try which could include withdrawing your help and support unless they get help. This might make the person angry and could affect your relationship with them, but it might be worth it because without help the person will only continue to get worse.

The bottom line is that treatment is voluntary and that if someone refuses all of your efforts to get help, you need to understand that you did not cause the illness and can't fix it. Sometimes the hardest thing to do when confronted with this situation is to accept the fact that you are powerless to help. Part of being able to do this is to learn as much as you can about the person's illness so that you understand their world. You need to understand why somebody is doing the things that they do. You need to know that it is part of the illness and not something done to hurt you. You need to be able to let go of wanting to help and yet be ready to be supportive when and if they become ready. It is hard to watch somebody you love make bad choices, but that is the reality.

Dr. Xavier Amador has written a book titled: *I Am Not Sick I Don't Need Help* which I recommend for further reading and tips on dealing with the problem.

- **Dr. Lawrence Haber is the director of the Family Resource Center- A Service for Families and Friends Dealing with Schizophrenia and Other Related Disorders at the Institute of Living.** Dr. Haber can be reached by phone at (860) 545-7731 or via email at [Lhaber@harthosp.org](mailto:Lhaber@harthosp.org).



## SCIENCE LIBRARY

### *Some current findings in the field of compulsive hoarding*

#### **Compulsive Hoarding: A Qualitative Investigation of Partner and Carer Perspectives**

Wilbram, M., Kellett, S., Beail, N. (2008). *British Journal of Clinical Psychology*, 47, 59-73.

This study examined the experiences of family members in caring for a person with compulsive hoarding. Ten people, all primary caregivers for a hoarding family member, were interviewed for the study. During the interview, caregivers were asked to discuss their own experiences of living with someone with compulsive hoarding, in the context of their family life. Five main themes were identified from the caregivers' responses. They included 'loss of normal family life,' 'the need for understanding,' 'coping with the situation,' 'impact on relationships,' and 'marginalization', or withdrawing from social life and distancing in their relationship with the individual with compulsive hoarding. Caregivers also identified adaptive strategies of coping with their family members who compulsively hoard. These adaptive coping behaviors included the accessibility and availability of support networks to help the caregiver cope with their added responsibilities. Additional coping behaviors endorsed by caretakers included acknowledging frustration with the hoarding *behavior*, but not the person, and emphasizing positive qualities of the individual with compulsive hoarding. This study emphasizes that caregivers who must tolerate clutter in their homes are affected both physically and emotionally. The conclusions of this study support the need for additional research to understand the factors that predict additional stressors for family members living with a person who hoards.

#### **Sex-specific Clinical Correlates of Hoarding in Obsessive-Compulsive Disorder.**

Samuels, J. F., Bienvenu, O. J., Pinto, A., Murphy, D. L., Piacentini, J., et al. (2008). *Behaviour Research and Therapy*, 46: 1040-1046.

This study investigated if there were differences in hoarding behavior between men and women with Obsessive-Compulsive Disorder (OCD). A sample of 151 men and 358 women with OCD were examined in this study. Of the men and women in the study, 40% of the men and 39% of the women had hoarding behaviors. Results of the study suggest *both* men and women with hoarding behaviors had thoughts related to items being even or equal and behaviors that related to organizing and arranging. Both men and women were also found to have rigid and perfectionist thoughts and behaviors. However, there were differences in the symptoms reported by men versus women with hoarding behaviors. In men, hoarding behaviors were associated with more religious and aggressive thoughts and checking behaviors, and more generalized anxiety. Among women, hoarding behaviors were associated with social phobia and post-traumatic stress disorder. Also in women but not men, hoarding behaviors were associated with greater reliance on other people and discomfort with making decisions or being left alone. Overall, these results suggest differences between men and women in terms of how hoarding behaviors develop and the ways in which hoarding is displayed.

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## To Discard or Not to Discard: The Neural Basis of Hoarding Symptoms in Obsessive-Compulsive Disorder

An, S. K., Mataix-Cols, D., Lawrence, N. S., Wooderson, S., Giampietro, V., et al. (2009). *Molecular Psychiatry*, 14 (3), 318-331.

Researchers have suggested that the brain structures of people with compulsive hoarding may be different from the brain structures of people with obsessive-compulsive disorder (OCD) and people without other mood or anxiety disorders. This study was interested in examining the patterns of brain activity in 29 people with OCD (13 with and 16 without hoarding symptoms) and 21 people without histories of mood or anxiety disorders. During the task, people viewed images of commonly hoarded items such as newspapers. They were asked to imagine the item was their own and they had to discard it, and then rate their feelings of anxiety in response to this task. While the people looked at the images, a machine was

taking pictures of the structure of their brain and recording what areas in their brain appeared to be used in completing the task. Compared to the groups of people without other mood and anxiety disorders, people with OCD (with and without compulsive hoarding symptoms) reported feeling more anxious while looking at the images. People with compulsive hoarding were found to have more brain activity in a region of the brain called the prefrontal cortex, which is located in the front of the brain, than did people with OCD and people without mood or anxiety disorders. These results suggest that increased brain activity in the brain region called the prefrontal cortex could be connected to the difficulties in emotion management, planning, and decision making experienced by people with compulsive hoarding.

## Research Opportunity for People with Depression and Clutter Problems

Do all of the following apply to you?

- Your home is so cluttered that you have trouble using your rooms or furniture?
- You have difficulty throwing things away, even when you don't need them?
- You are experiencing persistent feelings of sadness and hopelessness for weeks at a time?

The Anxiety Disorders Center at the Institute of Living/Hartford Hospital is conducting a neuroimaging (brain scan) study of people with both compulsive hoarding and depression. Participants will receive \$20 per hour. The studies are open to adults aged 18 to 65 who meet study criteria.

For more information please call or email  
The Anxiety Disorders Center  
(860) 545-7039  
or  
[adcresearch@harthosp.org](mailto:adcresearch@harthosp.org)



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## INSIDE VIEW: A PERSONAL ACCOUNT

***This anonymous personal account shares some of the ways hoarding affected the life of one of the patients who completed group treatment for compulsive hoarding at one of our centers, as well as her experience with treatment.***

Growing up I was always a messy kid, clothes all over the floor, things all over the bed and dresser. My mom was excessively neat and she would constantly be after me to clean up my room. When I went away to college, I remember my side of the room being a disaster, piles everywhere, and my roommate's side being neat and clean. Looking back, it's a wonder she put up with me. It was embarrassing and yet I did nothing about it. As I got older, I began to save more and more things. I would say to myself, well I might need this or this is important. I moved from place to place taking all this stuff and never even unpacking it. My stuff followed me everywhere. The collection kept getting bigger and bigger. Eventually, moving became a very difficult task.

I bought a house and things snowballed out of control. I had so much stuff in my house, you could not move freely about. The only space was a small pathway with things that kept falling down and blocking even the small path. It was a hazardous situation. I was constantly hitting things with parts of my body or tripping over things. There was no place to sit or eat and no where to cook.

Clothes, papers and stuff became piled everywhere. Dishes, cups, silverware and leftover food and drinks and empty food boxes, cans and bottles were buried in those piles. I could not find anything, so I had to go out and constantly buy more. I would buy more clothes, endless pairs of shoes, scissors and scotch tape because they would be buried. Anything I could not find, I would just buy again. My mom would come over and try to help me clean things up and a couple of weeks later the house would become extremely cluttered again. It got to the point where she would come over, open the door and start crying. Eventually, I could not let her come over because I did not want to see her burst into tears anymore.

My life was as messy as my house. I would not have anyone over. I became lonely and isolated. I became a prisoner in my own home. I always made excuses why people could not meet me at my house. I was overwhelmed by the clutter and yet paralyzed to do anything about it. I was very unhappy and my life was doom and gloom. I began to notice that there were shows on TV about other people who had similar problems. I almost could not believe it. After doing some research on the internet, I found the group treatment program for compulsive hoarding at Hartford Hospital. At this point in my life, I was 52 years old and disgusted with myself and the way I was living. I wanted to have a life again that included friends over, etc.

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I went to my first session and I was amazed. I realized that I had many more reasons not to continue hoarding than to continue. Starting was difficult because of the overwhelming nature of the problem. They taught me to start small. Pick an area and begin to sort things into piles – throw away, give away, find a place for. Once I did an area, even a small area, it was a great feeling of accomplishment and when I finally had my living room cleaned so I could sit on the couch and see the carpet again it was such a marvelous feeling. Don't get me wrong, it is a very difficult process, but it can be done. We learned how to set small goals and to reward ourselves when we accomplished them. The weekly meetings help you to stay on track and to learn useful techniques to overcome hoarding. I learned to question myself. Do I really need it? Can I live without it? Do I have a place for it? Surprisingly, I learned that I did not need many of the things I had saved, and that it was better to have the space than have the stuff. I began to fill up garbage bags and as I did I would feel better and better. I learned to organize, so I would know where to find my

stuff. It's an amazing feeling to actually know where things are. One of my most freeing moments in the program was when I realized that I did not have to save the millions of articles, magazines and newspapers that I had collected, because I could always research it on the internet. I believed that I had to hold onto the piece of paper to have the information. I am pleased with the progress I made in the program. Just realize that there is no instant fix. It's a work in progress.

My advice to anyone who is disgusted with the way they are living i.e., being surrounded by clutter, give this group treatment a chance and you will be pleasantly surprised. Be willing to analyze your thoughts, behaviors and beliefs. The more you begin to understand, the easier it will become to change. Be strong. You can do it.

◆ If you would like to contribute a personal story to the newsletter, please contact us at [adcresearch@harthosp.org](mailto:adcresearch@harthosp.org). We are interested in stories from people who hoard, as well as from their loved ones.

## Would you like to tell your story?

We get numerous requests from the media (newspaper, radio, and television programs) looking for people who are willing to share their personal experiences with compulsive hoarding.

If you are interested in appearing on television or in the newspaper to talk about hoarding, please email the Anxiety Disorders Center at [adcresearch@harthosp.org](mailto:adcresearch@harthosp.org). Please provide your name, age, and gender, as well as city, state, email, and phone number. Please let us know if you have a clutter problem or if your friend or family member has a clutter problem. If we receive such a request from the media, we will not give them your contact information, but will contact you to make you aware of this opportunity and to provide you with the information from the media.





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