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## Welcome!

This is the second issue of a newsletter produced by the New England Hoarding Consortium (NEHC). The NEHC is composed 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.

In this newsletter, we will provide you with the latest information coming out of our numerous research studies, as well as tell you about some studies that have been published by other researchers. You'll also get to read a personal story from a participant in one of our studies, as well as our responses to some of the important questions people ask on our web site. Some members of our staff have also prepared discussions of pressing issues that we hope you will find useful.

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, 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. Because we do not charge for the newsletter, we prefer to email the newsletter rather than mail it, so if you have an email address, please let us know.

We plan to update our information regularly, and will continue to send you new issues of the newsletter. Our sincere hope is that you will find it helpful, and that the information will give you new insights and ideas for working on the problem of compulsive hoarding.

David Tolin, Ph.D.



## 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 NIMH and the Obsessive Compulsive Foundation. He is co-author 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 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.

### 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, she holds an NIMH-funded grant to study features of compulsive hoarding. A recent NIMH grant developed a specialized cognitive and behavioral treatment for this syndrome. Additional research interests include the study and treatment of the hoarding of animals under the auspices of the Hoarding of Animals Research Consortium (HARC), and research on 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).



## 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.



The purpose of this part of the newsletter is to bring you up to date on the research activity in our programs. People who hoard, and family members of people who hoard, have graciously volunteered to participate in our research and help us learn more about the nature and treatment of hoarding. It seems fitting, therefore, that you should be the first to learn of the results of our studies. The study results we describe here are "hot off the press" and are our way of saying "thank you" to all who have helped us learn about hoarding.

Dr. Gail Steketee is the principal investigator of a study, sponsored by the National Institute of Mental Health (NIMH), called "Treatment of Compulsive Hoarding." Her colleagues on this project are Drs. Randy Frost and David Tolin. The treatment is an individual cognitive-behavioral therapy that involves helping people think more clearly and rationally about their possessions, teaching people how to make more effective decisions, motivational enhancement, and

help in reducing excessive acquiring. In the first phase of the study, 14 people with compulsive hoarding participated at Boston University and the Institute of Living in

Cognitive-behavioral therapy is an effective treatment for compulsive hoarding.

Hartford. They received 26 individual therapy sessions of CBT, including frequent home visits, over a 7-12 month period. We found that the severity of clutter, difficulty discarding, and acquisition decreased by a significant amount. At post-treatment, 50% were rated "much improved" or "very much improved" by the therapist. We also found that adherence to homework assignments was strongly related to symptom improvement. Next, we conducted a controlled trial in which 36 people who hoard were assigned at random to the cognitive-behavioral therapy or a waiting period in which they did not receive treatment. After 12 sessions of therapy, people who received the treatment showed significant reductions in hoarding severity, whereas people who waited for treatment did not. After 26 sessions, sixty-nine percent of people who received therapy were rated "much improved" or "very much improved" by the therapist, and 83% rated themselves as "much improved" or "very much improved." These rates of improvement are noticeably better than has been found in previous studies of the treatment of hoarding.

Drs. Randy Frost and Gail Steketee are the principal investigators of a study, sponsored by NIMH, called "Psychopathology of Compulsive Hoarding." The major clinical sites are at Boston University and the Institute of Living in Hartford. This is a large study in which we are interviewing people with compulsive hoarding and comparing them to people with obsessive-compulsive disorder and people with no mental health concerns. The aim of this study, which will continue for three more years, is to learn more about hoarding and associated mental health issues. One recent analysis from this study has been to learn more about the association between hoarding and other disorders. Although many people consider hoarding to be a form of OCD, this classification is not certain. Our analyses have shown that 17% of people who hoard

also have OCD. This is a high number; however, the fact that most people who hoard show no signs of OCD whatsoever raises questions about whether hoarding is really

Compulsive hoarding is not as strongly associated with OCD as was once thought.

a subtype of OCD. We also found that 57% of people who hoard meet criteria for major depressive disorder, 28% meet criteria for generalized anxiety disorder, and 29% meet criteria for social phobia. When we examined differences between hoarding



participants with and without generalized anxiety disorder (GAD), we found that people with hoarding + GAD demonstrated more severe hoarding symptoms, hoarding beliefs, and symptoms of anxiety and depression than did people with hoarding but no GAD. This research will continue for the next two years. If you live within 40 minutes of Boston or Hartford, please call us at 617-353-9610 (Boston) or 860-545-7039 (Hartford) to participate.

Dr. David Tolin is the principal investigator of a study, sponsored by Hartford Hospital, called "An Internet Survey of Compulsive Hoarding," assisted by Drs. Frost and Steketee. You might have received an email from our program inviting you to participate. Amazingly, over 2,000 people responded, making this by far the largest study of compulsive hoarding ever conducted! We are just now beginning the data analyses, but have already discovered some amazing things. First, we wanted to know more about the economic and social burden associated with hoarding. Among the respondents, 698 people met research criteria for clinically relevant compulsive hoarding (at least moderate clutter and at least moderate difficulty discarding, along with significant distress or

impairment). We examined work impairment days, which is calculated as the number of productive days lost because of an emotional or behavioral problem.

Compulsive hoarding is associated with more work impairment than almost any other psychiatric disorder.

Participants meeting diagnostic criteria for compulsive hoarding reported an average of 7 work impairment days in the past month. When we compared these figures to those in the National Comorbidity Survey, a large random survey of psychiatric disorders in the United States, we found that people with compulsive hoarding reported significantly greater work impairment than did people with all other anxiety, mood, and substance use disorders; work impairment was equivalent to that reported by individuals with psychotic disorders such as schizophrenia. Compared to people in the general population, people with compulsive hoarding were significantly more likely to report a broad range of chronic and severe medical concerns. Eight percent had been evicted or threatened with eviction due to hoarding, and 2% had a child or elder removed from the home by government agencies. These data show that compulsive hoarding represents a profound public health burden in terms of occupational impairment, poor physical health, and social service involvement.

To help us learn more about how hoarding affects loved ones, 793 family members and friends of people who hoard provided us with information. Of these participants, the largest portion, 44% were children of people who hoard; 21% were spouses or partners, 12% were siblings, 4% were parents, and 20% had other relationships (friend, grandchild, other). On average, family members in this study rated the person who hoards as having limited insight into the severity of their hoarding, and more than half described the person as either having poor

or no insight. People who lived with a person who hoards during their childhood years reported being significantly more embarrassed about their home, having fewer

Family frustration in compulsive hoarding equals or exceeds that seen in family members of people with schizophrenia.

visitors, experiencing more strain in their relationship with their parents, and having a more unhappy childhood than did people who did not grow up in a hoarding home. Most family members reported arguing with the person who hoards about the problem at least somewhat. We also studied family attitudes toward the person who hoards. Scores on a measure of family frustration equaled or exceeded those found for family members of hospitalized patients with schizophrenia in previous studies. Not surprisingly, more family frustration was significantly associated with poorer insight on the part of the person who hoards. These results show us that living with hoarding has adverse effects on the quality of the family relationships.

Dr. David Tolin is the principal investigator of a study, sponsored by NIMH, called "Neural Mechanisms of Compulsive Hoarding." 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 is associated with unique brain activity during decisionmaking. 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 three years. If you live within driving distance of Hartford, please call 860-545-7039 to participate.

Dr. David Tolin is the principal investigator of a study, sponsored by Hartford Hospital, of a study called "Neuropsychological Functioning in Compulsive Hoarding." Many of the people in our clinics and research programs have told us that they experience difficulty sustaining attention, trouble remembering things, difficulty making decisions, and other cognitive problems. In this study, we are using standard neuropsychological tests to measure a range of cognitive abilities in people who hoard, as well as people with obsessive-compulsive disorder and people with no history of psychiatric disorder. This study will continue for the next six months. If you live within driving distance of Hartford, please call 860-545-7039 to participate.

Finally, we are pleased to report the arrival

of three new books by members of the NEHC research team. *Buried in Treasures: Help* 

## New books on compulsive hoarding are available: --Buried in Treasures --Compulsive Hoarding and Acquiring

for Compulsive Acquiring, Saving and Hoarding (Tolin, Frost, & Steketee, Oxford University Press) is a selfhelp 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 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!

-David Tolin, Ph.D.



# **Questions & Answers**

Q: My mother is a compulsive hoarder and so are 4 other family members. I don't hoard, but I have a diagnosed impulse control disorder. Are there any studies being done that will explore the correlation of Impulse Control Disorders to hoarding and treatment methods? -Donna A, Mexico

**A:** We know that hoarding does run in families and that there may be a genetic basis for the excessive saving and clutter that we see in hoarding, although it will probably be a while before we understand just what traits are inherited genetically. One possibility is that impulse control problems underlie hoarding behaviors, at least for some people. We do see this clinically, often in the form of excessive acquiring. People may be unable to resist an attractive item, whether in a store or in the trash on the side of the street, and they buy or acquire things on impulse, regardless of any real need for items or ability to afford them. For example, in a filmed episode with Randy Frost that appeared on *Dateline*, one man went to the dumpster intending to discard several items but just as he was throwing the items into the bin, he became very excited about something he saw in the bin. He was unable to resist pulling out several more things, in the end taking away more than he discarded. This type of behavior is much like compulsive buying which is an impulse control disorder, akin to impulsive behaviors like gambling.

Our own research on the nature of compulsive hoarding examines the relationship of hoarding to various impulse control disorders (ICDs). For this study we use an Impulse Control Disorders Interview to identify potential problems with buying, kleptomania (compulsive stealing), gambling and explosive angry episodes

to determine whether any of these are related to hoarding. We have not yet finished our study so we are not yet sure of the relationship in our population of adults in their middle and later years. However, there are some preliminary findings from our colleagues Dr. Meredith Coles and Laura Cook in a young sample of college students. In their study, hoarding was more closely related to obsessive compulsive symptoms than to ICDs of kleptomania (stealing), compulsive gambling and trichotillomania (compulsive hairpulling), but not surprisingly, hoarding was closely related to the ICD of compulsive buying. Thus, hoarding seems to be closely linked to compulsive buying but not other impulsive behaviors in college students. We don't yet know whether this will hold true for older adults. We'll keep you posted.

Dr. Gail Steketee

Q: I was wondering if anyone has looked into a hereditary connection with the hoarding issue? My concern is that our children, whom both appear normal, may develop this later in their life. Is this something that I need to be on the lookout for? - Brenda H, Illinois

**A:** 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 OCD Collaborative Genetics Study 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. Stay tuned.

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.

Dr. Randy Frost

Q: My mom has always been a hoarder and it has progressively gotten worse. What can

I do? Do I without her blessing clean her house for her? She says that she has no time. Where do I begin to help my mother? - Angie G, Indiana

A: This is one of the most common questions we hear. It's terribly frustrating to see a loved one suffer from hoarding, especially when he/she doesn't seem as bothered by it as you are, or is not as motivated to change things as you are. How can we make our loved ones see that this is a problem, get them to work on the clutter, or make them get the professional help they need?

We need to remember that in most cases, we can't *make* our loved ones do much. Assuming that your mother is an adult who is legally competent to manage her own affairs, and the clutter is not immediately lifethreatening, she has the right to hoard, even though the hoarding might have terrible consequences for her quality of life and be extremely frustrating to you.

Should you just clean out your mother's house without her blessing? We generally recommend against doing so, for both legal and practical reasons. From the legal perspective, assuming that this is your mother's house and her possessions, it would be illegal to take her things away without her permission or a court order. From a practical perspective, our experience has been that this approach rarely has the desired effect. Remember, hoarding is not just a house problem; it's also a person problem. Cleaning up the house won't do anything to help your mother overcome the psychological obstacles and deeply ingrained behavior patterns we know to be associated with hoarding. We have seen lots of examples in which family members or social service agencies cleaned out someone's house, only to see it quickly become cluttered againsometimes even worse than it was before! It's also important not to sacrifice the family



relationship just to get the house clean, which the forceful approach would probably do. So a collaborative approach is much more likely to get you the results you want without damaging the relationship.

The key to the collaborative approach is to alter the way you bring up the topic to minimize the likelihood of getting a defensive reaction. Often, it's tempting to start arguing with the person, trying to persuade them to see things the way you do. This kind of direct confrontation rarely works. We find that the best way to help people increase their motivation to work on the problem is to start with three key assumptions:

- 1. Ambivalence is normal.
- 2. People have a right to make their own choices.
- 3. Nothing will happen until the person is ready to change.

Here are some general principles to guide your conversations:

- 1. *Show Empathy.* Showing empathy doesn't necessarily mean that you agree with everything the person says. But it does mean you are willing to listen and to try to see things from the other person's perspective.
- 2. *Don't Argue.* There is simply no point in arguing about hoarding. The harder you argue, the more the person is likely to argue back. The only solution is to get out of the argument.
- 3. *Respect Autonomy*. Remember, most of you are dealing with an adult who has

freedom of choice about his or her own possessions. Try to engage your loved one in a discussion (rather than an argument) about the home and his or her behavior. Ask your loved one what he or she wants to do, rather than just telling him or her what you want: "What do you think *you* would like to do about the clutter in the home?" "How do *you* suggest we proceed?"

4. Help the person recognize that his/her actions are inconsistent with his/her greater goals or values. Ask the person about his or her goals and values. "What's really important to you in life?" "How would you like your life to be five years from now?" "What are your hopes and goals in life?" Discuss whether or not the person's acquiring or difficulty organizing or getting rid of things fit with those goals and values. This is most effective if you ask, rather than tell. "How does the condition of your home fit with your desire to be a good grandmother?" "You've told me that friendships are very important to you; how well can you pursue that goal, given the way things are right now?"

-Dr. David Tolin

♦ If you have a question regarding compulsive hoarding you would like answered, contact us by emailing us at adcresearch@harthosp.org.

# **Compulsive Hoarding Titles from the Research Team**

## **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

reasure

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.

✓ Treatments That Work Compulsive Hoarding and Acquiring Therapist Guide Gail Steketee Randy O. Frost ✓ Treatments That Work Compulsive Hoarding and Acquiring A scientifically and clinically proven program to help you beat your bearling problem es tips and tools for filing, sorting, and orga Gail Steketee • Randy O. Frost

"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**

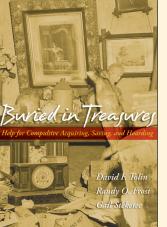
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# SUMMARY OF AVAILABLE SERVICES AT THE INSTITUTE OF LIVING

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 individual and/or group therapies. All services are carried out by trained medical 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.

Diagnostic Evaluation	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.
Individual Therapy	These therapy sessions implement cognitive-behavioral therapy as a means to change ones behaviors and attitudes toward clutter and accumulation. The sessions last 45-50 minutes and take place within the clinic.
Group Therapy	Group therapy is an additional treatment option, and consists of groups of at least six people within the area. Group members travel to clients' homes, which must be located within 30 minutes from Hartford.
In-Person Family Consultation	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.
Telephone Initial Evaluation	Individual initial assessment is also available over the phone and lasts about 2 hours.
Telephone Therapy	Therapy sessions can be administered over the phone. Each session lasts 45-50 minutes.
Telephone Family Consultation	Family consultations also have the option of being carried out over the phone. These sessions also last approximately 45-50 minutes.
In-Home Consultation	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.



# BOSTON<br/>UNIVERSITYSUMMARY OF AVAILABLE SERVICES<br/>AT BOSTON UNIVERSITYSCHOOL OF SOCIAL WORK

The Boston University services for those with compulsive hoarding and their families include initial telephone screening and referral, diagnostic assessment, group treatment, and support groups; individual treatment is offered on a space available basis. A description of the services offered is provided below. Additional information can be obtained by calling the Boston University Hoarding Project at (617) 353-0815 at the School of Social Work.

Initial Telephone Screening and Referral	
Diagnostic Assessment	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.
Group Treatment	Group therapy is available at selected start times for at least six people with hoarding who live within 40 minutes of Boston so group leaders can visit clients' homes periodically.
Individual Therapy	Limited individual therapy is available using cognitive-behavioral therapy to change behaviors and attitudes toward clutter and saving. Sessions of 50 minutes take place at the BU project site.
Support Groups	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.



## Professional Organizer Techniques for Working with Clutter

People with clutter (a little or a lot) are turning to professional organizers to help them reduce and manage their belongings. While every professional organizer will have a different personality, approach, and qualifications, there are common underlying themes that help us structure our work with clients.

- Categorize. This means to separate like with like and create boundaries between them. I start nearly every organizing job with this technique. The benefits are: you can see how many of an item you actually have, you can start making decisions about which ones you don't need any more, you can see how much space you need to store and keep the items in good condition.
- 2. Label. A critical piece to keeping things organized. Labeling may feel a bit childish at first, but think of these benefits: you can find things and put things away easier, other family members can help put things away, you have an immediate visual clue as to how your space is arranged (say kitchen cabinet, for example), and you can start developing new habits and systems more easily.
- Create and revise systems. Getting systems in place for things like mail, laundry, and meals is important. Equally important is tweaking them as you move forward – not to water them down until they don't exist, but to

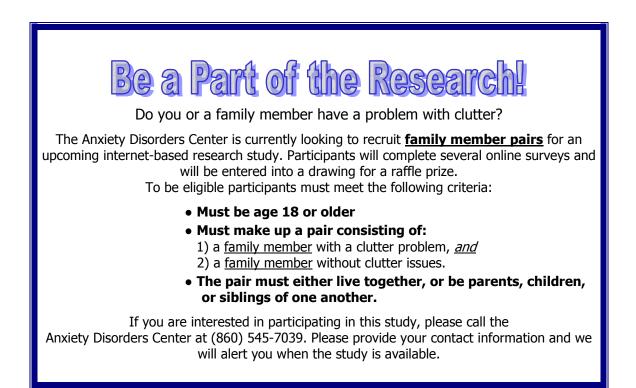
make them work for you. Many 'traditional' organizing techniques and systems do not work for clients with lots of clutter and can set clients up for failure.

- 4. Find charities and other organizations to take donations. I usually spend a good deal of time researching these options, asking around with the local shopkeepers and neighbors. In my experience, letting go of possessions is easier when the possessions are being put to another use. Local missions and shelters are an excellent option for donations and are usually grateful for them. I even found one who took a few hundred 'singleton' socks!
- 5. Understand that buying organizing tools won't necessarily make you organized. Professional organizers are knowledge-banks of various tools that help streamline life. However, bins and boxes, for example, don't come with arms to put things inside of themselves! Tools need to be introduced slowly, roughly at the same rate of change that behaviors and habits seem to be changing. I use 'free' items before upgrading to an expensive option. Shoe boxes, for example, are excellent tools to structure new mail systems. If a client is still using them after a few weeks, we can then invest in something more substantial.
- 6. Start with safe areas. Build up small successes and confidence before



tackling more difficult rooms or areas.

7. Be consistent. If you are working with a professional organizer, it's critical to keep him or her around on a consistent basis. That might mean once a week or once a month, depending on your budget. The organizing shows on television lead us to believe that organizing can be done in a few short hours, when in reality this is not the case. Real change takes longer! ◆ Liz Farrell is the founder of Gone By Noon LLC (www.gonebynoon.com), a professional organizing company based in Lyme, Connecticut. She holds a certificate of study with the National Study Group on Chronic Disorganization and serves on the Board of the National Association of Professional Organizers Connecticut Chapter. A member of the Connecticut Better Business Bureau, Liz is fully insured and bonded. She has helped over 100 clients since 2004.





## Science Library

Some current findings in the field of compulsive hoarding

Significant Linkage to Compulsive Hoarding on Chromosome 14 in Families with Obsessive-Compulsive Disorder: Results from the OCD Collaborative Genetics Study

## American Journal of Psychiatry, 164:493-499, 2007, J. Samuels, Y.Y. Shugart, M.A. Grados, et al.

Individuals with obsessive compulsive disorder (OCD) who have compulsive hoarding behavior are clinically different from other OCD-affected individuals. The objective of this study was to determine whether there are chromosomal regions specifically linked to compulsive hoarding behavior in families with OCD. The authors assessed for linkage in 219 OCD families collected as part of the OCD Collaborative Genetics Study. The authors treated compulsive hoarding as the trait of interest and also grouped families into those with and without two or more relatives affected with compulsive hoarding. In families with two or more hoarding relatives, there was significant linkage of OCD to chromosome 14, whereas in families with fewer than two hoarding relatives, there was suggestive linkage to chromosome 3. The findings suggest that a region on chromosome 14 is linked with compulsive hoarding behavior in families with OCD.

# Categorization in compulsive hoarding

### Behaviour Research and Therapy, 45:63-72, 2007, J.P. Wincze, G. Steketee, R.O. Frost

This study examined categorization processes in people with clinically significant compulsive hoarding problems. Twenty-one participants with primary compulsive hoarding, 21 with OCD without hoarding, and 21 people with no psychiatric disorder completed three categorization tasks. Hoarding and OCD participants reported significantly more distress prior to each of the three tasks than did controls. On tasks sorting common household items, the groups did not differ on the number of piles created nor on the amount of time taken to sort. However, on a task sorting personally relevant items, hoarding participants took more time, created more piles, and reported more anxiety than did nonpsychiatric controls. Hoarding participants also took more time than the OCD group, and tended to create more piles. Hoarding severity was associated with the number of piles created, but only when the objects were personally relevant. These results suggest that people who hoard have difficulty categorizing their possessions, in part because of an under-inclusive thinking style in which they have difficulty grouping like items together.

# Paroxetine treatment of compulsive hoarding

## Journal of Psychiatric Research, 41:481-487, 2007, S. Saxena, A.L. Brody, K.M. Maidment, L.R. Baxter Jr.

Compulsive hoarding, found in many patients with obsessivecompulsive disorder (OCD), has been associated with poor response to serotonin reuptake inhibitor (SRI) medications in some reports. However, no prior study has measured response to pharmacotherapy in people who hoard. In this study, 79 patients with OCD (32 of whom hoarded) were treated with the SRI antidepressant paroxetine. Hoarding patients responded as well to paroxetine treatment as did non-hoarding OCD patients. However, we note that neither group responded particularly strongly to the medication.



## **Task Forces Team Up to Respond to Hoarding Problems**

Across the country, communities urban and rural, large and small are responding to public cases of compulsive hoarding by forming interdisciplinary task forces. With representatives from fields and professions such as public health, fire, police, social work, animal control, code enforcement and mental health, task forces seem to be a mechanism through which costly and time consuming cases of hoarding are increasingly being addressed in a strategic way.

While the exact number of hoarding task forces is unknown, it is estimated that between 15-20 inter-agency, interdisciplinary task forces exist in major U.S. cities. A much larger number of intra-agency and intra-city/county task forces that serve the needs of one jurisdiction through coordinated efforts of a city or county's fire, police, nursing, health and social service departments. Additionally, task force efforts are also known to exist in Canada as well as the U.S.

### By Christiana Bratiotis, MSW

As the dimensions of compulsive hoarding problems are far-reaching and impact a number of aspects of the life of the person who hoards (including housing stability, personal health, personal safety, environmental and sanitation) and are often complicated by mental health issues (such as depression, anxiety, phobias, inattention/distractibility and perfectionism), task forces bring myriad resources to bear on hoarding problems.

Although many aspects of the hoarding problem have begun to be systematically and empirically studied, task forces as a response to cases of compulsive hoarding have not yet been examined in this way. A qualitative comparative case study is currently underway at the Boston University School of Social Work; the findings of this research will provide insight into the formation, operation, successes, challenges and implications of task force intervention. For further information about the task force study, contact: Christiana Bratiotis, MSW, 617.353.5666 or cbrat@bu.edu.

# **Interested in being interviewed?**

From time to time, we get requests from television programs, magazines, and newspapers to do interviews with individuals who have 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 <a href="mailto:adcresearch@harthosp.org">adcresearch@harthosp.org</a> or call (860) 545-7039. 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 a newspaper or television program, we will not give them your contact information, but will contact you to provide you with the information from the newspaper or television program.



## **Hoarding and Housing Problems**

The accumulation of a large number of possessions in the homes of people with compulsive hoarding can lead to a number of very serious problems over time. These include danger of injury due to falls in the home or items falling on household members, health problems, danger of fire, and legal problems.

Danger of falling: Items like books and paper are often piled on one another and on the floor or furniture in an effort to create more space. These piles are often unstable and fall over. This can result in littered pathways in the home, which can lead household members to fall and potentially injure themselves. Piles of possessions, such as boxes of books or overstuffed shelves, can directly fall on household members, potentially severely injuring them. This is particularly dangerous for children, elders, and pets.

<u>Health problems</u>: When there is a lot of clutter in the home, infestation by insects and rodents can become a problem. It is both easier for these pests to make a home among the clutter relative to an uncluttered home and more difficult to treat the problem once the pests take up residence. In addition, because it is often difficult to clean a home that is very cluttered, dust and mold accumulate over time and can cause respiratory or other problems that may be difficult to diagnose.

<u>Danger of fire</u>: Clutter, particularly in the form of paper, can be a fire hazard. Oftentimes, paper,

## By Cristina M. Sorrentino, PhD, LCSW

such as mail or newspapers, may be directly placed on the stove; other times, paper simply encroaches on the stove because adjacent areas are cluttered. Complications from a heating system in disrepair can also lead to fire hazards. For example, individuals with hoarding may not be able to actually access the heating system due to clutter or may feel shame about the condition of the home, preventing them from calling a repair person. As an alternative, they may use space heaters to provide heat, overloading power outlets or running power cords over or under flammable objects. If there is a fire or a medical emergency, the clutter in the home can prevent fire fighters or emergency personnel from entering the home or from accessing the person in need. Situations like this have resulted in death of the individual with compulsive hoarding or other family members.

Legal problems: It is not unusual for compulsive hoarding to result in legal problems. Concerned neighbors or family members may seek help from the department of public health or the fire department. Because of federal and state law outlining conditions that constitute a fire, personal, or public health hazard, an individual with compulsive hoarding may be evicted or may have his or her home condemned. Where children, elders, disabled people, or pets are in the home, protective services may need to step in to remove humans and animals endangered by the problem.



# **Personal Story...** A personal look into Compulsive Hoarding

From M who received 26 sessions of treatment and is now attending a support group for those who completed treatment for compulsive hoarding:

I've been meaning to contact you. Just last night I attended my second support group meeting led by two of your staff members for people like me who participated in the hoarding treatment study. As you and I discussed some time ago, a support group is something I thought would be helpful for me. I found both meetings to be a great reminder of techniques you and I discussed during individual treatment. It was also an interesting opportunity to hear what situations others are dealing with, and was just plain inspirational as we leave with a commitment to handle some personal hoarding situation - homework really works for me! I'm very pleased this group is available, and am thankful to whoever is making it possible. Also, congratulations on your new book. We looked at copies last night and although I've only cursorily looked through it so far, I can tell it too will inspire me when I can devote time to a more thorough reading.

I will be forever grateful for your time and guidance helping me with my issues around hoarding, and frankly transforming my home life! I feel I gained enormous *necessary* insight into the varied reasons why I hold onto (too many) things. I think this insight is what made it

possible for me to make changes that seem to be lasting. Too many of those clutter and organization books suggest an action approach based upon organizational systems that work for the author or someone else. But they don't talk about the very deep-seated individual stuck points that are in the way for collectors like me. During treatment I gained some personal insights that have led to my more liberated approach to looking at and discarding stuff, even sentimental items which are clearly the hardest thing for me. It has been very interesting for me to listen to others at these two recent support group meetings. I'm reminded just how individual this problem is -considering what to do with my daughter's childhood clothes can lead to my undoing, whereas newspapers and journals, reusable boxes and containers, or "free stuff," etc., etc., can undo someone else. Yet the techniques learned in the treatment you've developed obviously have assisted us all.

Thanks for all your help.

## М

◆ If you would like to contribute a personal story to the newsletter, please contact the Anxiety Disorders Center at <u>adcresearch@harthosp.org</u>. We are interested in stories from people who hoard, as well as from their loved ones.



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