Tompkins County Hoarding Task Force Field Guide

Created by the Tompkins County Task Force on Hoarding July 2010

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This *Tompkins County Hoarding Field Guide* is designed for use by persons who may come in contact with hoarding in the course of their work: nurses; social workers; mental health professionals; social service caseworkers; landlords; county, town and city employees, etc.

Just as people with hoarding behaviors may feel overwhelmed and not know what to do about their situation, social service agencies, landlords, and others who try to help them to create safer living conditions may feel overwhelmed as well. We believe that by addressing compulsive hoarding in a more coordinated way we can avoid 'last-ditch', high-cost crisis interventions and help to prevent evictions or other loss of housing.

Our hope is that this Guide will give Tompkins County professionals an increased understanding of the complexities of compulsive hoarding behavior, and valuable information on the assistance available locally.

If you have picked up this Guide and are looking for assistance for a family member or friend, we urge you to call Protective Services for Adults at the Tompkins County Department of Social Services for assistance and support at (607) 274-5323.

For those who are looking for a deeper understanding of the phenomena of hoarding, there is a sample bibliography at the end of this Guide, as well as a list of current web resources.

<u>Compulsive hoarding</u> refers to the acquisition and retention of a large number of possessions, originating (as with most compulsions) in an attempt to decrease stress and anxiety. This serious problem can lead to numerous health and security hazards, eviction, and homelessness. Hoarding can be a feature of certain mental health disorders, and can be caused or exacerbated by problems associated with increasing age or physical disabilities.

Hoarding is defined as¹:

- The acquisition of, and failure to discard, a large number of possessions that appear – to outsiders – to be useless or of limited value; *resulting in*:
 - $\circ~$ Living spaces that can't be used for their intended purpose due to the clutter; and
 - Significant distress or impairment in functioning caused by the hoarding.

The most commonly hoarded items are:

- > Newspapers
- > Clothing
- > Containers
- ≻ Mail
- ➢ Notes and lists
- Personal papers
- > Animals

Some Basic Information about Compulsive Hoarding Disorder

Compulsive hoarding behavior will vary from case to case, but the following general facts may be useful to Tompkins County professionals coming in contact with those who hoard:

- > Hoarding affects men and women across all socio-economic and ethnic groups
- Approx 0.4- 2.0% of the population exhibit hoarding behavior. In Tompkins County, this translates to an estimated 405-2023 people suffering from compulsive hoarding
- > Hoarding is a neurological disorder, *not* a result of being lazy or 'weak-willed'
- ➢ Hoarding is a compulsion
- > Compulsive hoarding and acquiring may involve an impulse-control disorder
- > Hoarding can be resistant to traditional talk therapy and medication
- Hoarding may have a genetic component
- > Onset of hoarding behavior can be as early as age 10
- Typically, hoarding begins with clutter and difficulty discarding items, but progresses over time to become unmanageable and overwhelming
- Those suffering from compulsive hoarding behavior may have very little insight into their symptoms, and may exhibit a lack of motivation to reduce their possessions
- Attempts to reduce excess possessions can cause extreme anxiety
- > Those who hoard are often depressed, anxious, and experience social phobias
- Severity often increases with age

¹Frost, R. O., & Hartl, T. L.

Possible Co-Existing Mental Illnesses

Compulsive hoarding behavior may be a feature of a mental illness, or be exacerbated by an underlying condition. Professionals working with those who suffer from compulsive hoarding should keep in mind the possibility that these other issues may interfere with assistance and treatment. Some of the disorders that may be involved include:

- Obsessive-Compulsive Disorder (OCD)
- > Obsessive-Compulsive Personality Disorder (OCPD), and other personality disorders
- Impulse-Control Disorders (e.g. compulsive shopping, gambling)
- Anxiety Disorders
- Attention Deficit Disorder (ADD)
- > Dementia, stroke, and other neurodegenerative disorders
- Eating Disorders
- > Autism
- Mental Retardation
- Schizophrenia
- Tourette's Syndrome
- Trichotillomania (compulsive hair pulling)

What Motivates Compulsive Hoarding Behavior?

The following lists the most common feelings expressed by those who suffer from compulsive acquiring and retention of possessions:

- > Fear of losing important items that might be needed later
- Distorted beliefs about the importance and value of possessions
- Excessive emotional attachment to possessions -- hoarders can experience extreme grief-like feelings of loss in response to getting rid of anything
- > Making decisions is extremely difficult and anxiety-producing
- ➢ Fear of making the "wrong" decision
- Worry about wasting: excessive sense of responsibility
- Wanting to take care of hoarded items
- ➤ Wanting to make sure hoarded items have a good home
- ➢ Difficulty with:
 - \circ Perfectionism
 - \circ Indecisiveness
 - Avoidance
 - o Attention
 - Procrastination
 - Organization

What should Tompkins County professionals know about those who compulsively hoard?

These guidelines are offered by peer professionals who have worked with compulsive hoarders:

- Clients may recognize that they need help, but are unable to move at the same pace as field workers to clean the home and reduce the number of possessions.
- Clients need to be clear about who you are, why you are there, and what is expected of them.
- Clients need to have a clear description of what needs to be done to solve the immediate problem, such as avoiding eviction or loss of housing assistance.
- Clients need help in setting specific, achievable, short-term goals.
- Clients usually believe that every item they possess has value. It is counterproductive to argue this point, or to refer to their possessions as "junk" or "trash".
- > Clients may experience extreme stress when trying to remove items from the home.
- Clients need help in finding creative solutions to reduce their possessions.
- Clients need to be reassured that it will be possible to replace an item or find information again at a future date, if they feel they might need it.
- Clients need to feel that the removed items are being put to good use.

Health and Safety Risks of Compulsive Hoarding

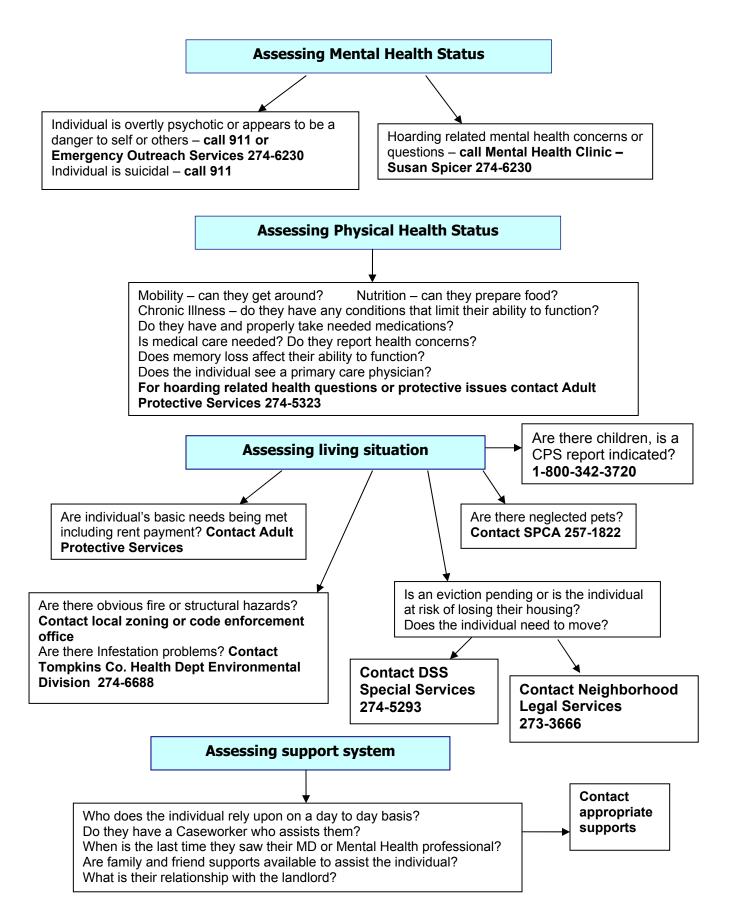
- Safety Hazards: Clutter can cause limited mobility, with an increased risk of falls and injuries. Some people who hoard can be socially isolated, and this can increase the likelihood that assistance will not be immediate in the event of an injury. Emergency response personnel may not be able to navigate a cluttered house quickly if called.
- Health Hazards: Excessive clutter can lead to inadequate cleaning. Homeowners may not be able to prepare food, or may be at risk of food contamination. In some situations, rotting food items can lead to rodent and/or insect infestations. Animal hoarding can carry the risk of many diseases and parasites.
- Fire Hazards: Clutter can block doorway and window exits, making leaving the home very difficult in an emergency. Boxes, paper, clothing, and other items are extremely flammable, and will add potent fuel to a fire.
- <u>Community Risk</u>: Structural damage can lead to building condemnation. Infestations can affect whole buildings and neighborhoods.

Can Compulsive Hoarding be Treated?

There is help and hope for those who suffer from compulsive hoarding behaviors, if the person wants and seeks help. However, because hoarding can be a feature of a number of different illnesses, and because another illness may underlie the hoarding behavior, there is no one treatment that will work for every person. Treatment may be a lengthy, sometimes difficult process, and those who suffer and their loved ones should understand that there are no quick, easy answers.

Hoarding has been shown to be resistant to standard talk therapy, and in many cases medications are not considered effective.

- Cognitive Behavioral Therapy (CBT) has been found to be the most effective treatment, as it develops connections between the person's thoughts, feelings, and behaviors. With CBT, there is a strong emphasis on changing the client's behaviors, not just understanding the motivations. CBT challenges the thoughts and beliefs about the client's attachment to the hoarded items, and addresses the need to collect new items.
- Changing behaviors is an effective way to increase functioning, increase rational thinking, and decrease negative feelings.
- > Group treatment can be more effective than individual treatment.
- Effective treatment involves education and intervention that targets specific aspects of hoarding.
- The client must work to reduce their possessions themselves, usually with the assistance of a therapist and an organizer. This process may begin with visualizing discarding items, gradually working toward actually discarding items – first with support, then on their own. The client's tolerance for this will likely be exceptionally low and will build only very gradually, so this can be a slow, lengthy process.
- It is counterproductive to treatment for others to come into the home and "clean it out" the client's trust will be lost and, as the behavior itself has not been addressed, the hoarding will continue and the home will quickly fill up again. In addition, this sort of intervention can provoke serious emotional reactions. If this type of forced intervention is deemed medically or legally necessary, mental health personnel should be on hand when the client re-enters the home, and available for ongoing support.
- Clients will work with the therapist to develop strategies for preventing relapses into old behaviors.



<u>Animal Hoarding</u>

Criteria used to identify animal hoarders:

- > Obsessive attempt to accumulate or maintain an unusual number of animals.
- Animals are not provided with the minimum standards of care (nutrition, sanitation, space, shelter and veterinary care). This neglect often results in overcrowding, illness, starvation, and death.
- Denial about the lack of care that the animals receive and also about the deteriorating condition of the animals and their environment.
- Animal hoarders generally refuse to give away any animals, often believing that no one will care for them as well or love them as much.

Hazards posed by animal hoarders:

- Disease risk to humans, spread through contact with animals, their feces and/or saliva, (rabies, ringworm, scabies and a variety of intestinal parasites)
- Disease risk to other animals (including companion animals and wildlife)
- Structural damage to buildings because of rot caused by urine, feces and/or decaying animal carcasses
- Attraction of pest and other nuisance wildlife (rats, mice, flies, etc.)
- ➤ Health and safety risk to emergency responders

What to do if you suspect an animal hoarding situation:

Try to gather as much information as possible about the situation:

- Basic personal information (owner name, address, etc.)
- How many animals are involved?
- ➤ Where are the animals located?
- > What conditions are the animals being kept in?
- > Do the animals have food and water available?
- Do the animals appear to be sick, underweight, or in serious need of routine care (long nails, badly matted fur, etc.)?
- > Are there dead animals present on the property? Where?
- Does the owner seem open to the possibility of re-homing animals and receiving assistance for the remaining ones?

In Tompkins County, please report these situations to the SPCA of Tompkins County, Field Services Department at 607-257-1822 ext. 229.

For emergencies which cannot wait until morning, you may call the Field Services emergency cell phone at 607-592-6773.

Additional resources

The Hoarding of Animals Research Consortium (Tufts Vet School) http://www.tufts.edu/vet/cfa/hoarding/abthoard.htm

Animal Hoarding – An in depth look at the phenomenon <u>http://www.animalhoarding.com/How-Animal-Hoarding-Develops.html</u>

Animal Cruelty and Fighting (HSUS) http://www.hsus.org/acf/cruelty/publiced/animal_cruelty_laws_by_state.html

Relevant Fire and Building Code Violations in Tompkins County

The state of New York, as well as some municipalities within the state, has a housing code that applies both to rental and to owner-occupied dwellings. These codes specify minimal standards of cleanliness, access, and safety that must be met. The violations listed below apply throughout upstate New York, and in Tompkins County and there are no local rules that supersede them. For more information, please refer to the <u>Fire & Building Codes of New York State</u>.

Major violations include the following:

Exits

- Blocking exits
- Storing or placing items that obstruct the exit from stairways, passageways, doors, windows, fire escapes or other means of exit.
- Not having aisles clear (at least 30 inches)
- Blocking or storing items on the fire escape

Kitchen

- Non functional stove*
- Non functional refrigerator*
- ➢ Non functional sink*
- Non functional appliances*

Bath

- Non functional sink*
- Non functional bathtub*
- Non functional water heater or central water-heating equipment*

General

- Obstructed exits
- Unsanitary exterior or interior conditions
- > Pets or animals not kept in an appropriate manner or under control
- > Allowing the building and structure to get infested with insects, vermin, or rodents
- > Storing junked vehicles, equipment or materials in open areas
- Discarding or abandoning refrigerators, and similar equipment with locking mechanisms on premises accessible to children, without first removing the locking devices or the hinges of the doors

* Usually the landlord is responsible for repairing these items, but a tenant can be if the lease so requires. If landlord is responsible then tenant must provide access to the premises.

Hoarding Resources

Tompkins County Mental Health – 201 E. Green St., Ithaca, NY 14850

Outpatient Clinic – - addresses the clinical needs of chronically mentally ill adults. Needed specialized psychotherapy is provided in both individual and group settings. Education regarding mental illness, and medication management also provided. Phone – (607) 274-6230 Fax – (607) 274-6258

Other Outpatient Mental Health Resources

Mental Health Association 614 W. State St., Ithaca, NY 14850 Private, non-profit organization that provides advocacy, education, and information about options concerning mental health issues, services and providers Phone – (607) 273-9250

Guide to Mental Health Professionals – online information for finding a mental health professional with an updated list of local mental health professionals provided by the Mental Health Association of Tompkins County http://www.mhaedu.org/tguideintro.shtml

Family and Children's Services

204 N. Cayuga St., Ithaca, NY 14850

Clinical Treatment and Support Services – Primary treatment resource for adults, children and adolescents. Services include assessment, referral and short-term clinical counseling for EAP. Diagnostic, treatment and consultation services, psychiatric evaluations for medication treatment and crisis and mental health outreach/support services are available. Adult and Family Mental Health Program – individual, couple, family and group counseling for coping with difficulties or life challenges. Phone: (607) 273-7494 Fax: (607) 273-7484

Therapists who work with clients who hoard

Tompkins County Mental HealthOutpatient Clinic – - addresses the clinical needs of chronically mentally ill adults.Needed specialized psychotherapy is provided in both individual and group settings.Education regarding mental illness, and medication management also provided.Phone – (607) 274-6230Fax – (607) 274-6258

Joanne Zager, Ph.D. NY State Licensed Psychologist 118 Park Lane Ithaca, NY 14850 607-272-6353 jzager@twcny.rr.com

Gail Zussman, MSW, :CSW-R 119 E. Buffalo Street Ithaca, NY 14850 (607) 387-5925 Email: gzussman@twcny.rr.com I have been in practice since 1980.I work with individuals, couples and families of all ages. I am able to practice EMDR.

Tompkins County Public Health Department 401 Harris B. Dates Dr., Ithaca, NY 14850

Environmental health – Investigates/provides:

- ➢ Raw sewage
- > Reports of mold in either a landlord situation or home owners with referral from MD
- Burning complaints
- Food garbage outside a residence
- Private well water testing
- Indoor air quality with MD referral Phone: (607) 274-6688

Fax: (607) 274-6695

Certified Home Health Agency, Homecare division

Includes: skilled nursing, intravenous, physical, speech, enterostomal, and occupational therapies, and home health aide services. Phone: (607) 274-6656 Fax: (607) 274-6684

Other Homecare Resources

Certified Home Health Agency

Visiting Nurse Service of Ithaca and Tompkins County 138 Cecil A. Malone Dr., Ithaca, NY 14850

Provides home health services for both acute and long term care patients in their own place of residence. Services include: Home Health aides, Skilled Nursing Services, IV Therapy, Physical, Speech and Occupational therapy and Medical Social Work. Phone: (607) 273-0466 Fax: (607) 277-1494

Licensed Homecare Agencies – provide in home aide services for personal care and household tasks

Caregivers 521 W. State St., Ithaca, NY 14850 (607) 275-0238

Classen Home Health 310 Taughannock Blvd., Ithaca, NY 14850 (607) 277-1342

Comfort Keepers (607) 272-0444

Community Home and Health Care 138 Cecil A. Malone Dr., Ithaca, NY 14850 (607) 273-7780

Redmoon Private Caregivers and Consultants

222 S. Albany St. #1, Ithaca, NY 14850 (607) 254-6090

Stafkings Healthcare Systems 224 S. Fulton St., Ithaca, NY 14850 (607) 273-5335

Registry – Women's Opportunity Center 315 N. Tioga St., Ithaca, NY 14850 (607) 277-7686

Tompkins County Department of Social Services

320 W. State St., Ithaca, NY 14850

- Emergency Services for Adults Eviction prevention, emergency assistance for homeless shelter applicants, relocation assistance, security deposit letters, moving expenses, furniture. Housing specialists. Phone: (607) 274-5293 Fax: (607) 274-5314
- Protective Services for Adults Investigation of abuse and neglect of adults and seniors with a disability, case management, financial management, referrals, applications/advocacy for benefits and services, assistance with locating safe housing, guardianship Phone: (607) 274-5323 Fax: (607) 274-5666 email: <u>liz.norton@dfa.state.ny.us</u>
- Child Protective Services Children's intake and protective services investigates all reports of child abuse and maltreatment and provides initial assessment for protective and preventive services to families and children.
 Phone: (607) 274-5296 (Supervisor CP#1) Fax: (607) 274-5673
 Phone: (607) 274-5321 (Supervisor CP#2)

Tompkins Care Connection (Long Term Care Services) – information, referral, in-home assessment, nursing home assessment, homecare services for eligible Medicaid recipients, homecare services for eligible seniors who do not qualify for Medicaid, personal emergency response systems Phone: (607) 274-5278 Fax: (607) 274-5666 email: <u>liz.norton@dfa.state.ny.us</u>

Other Social Services

American Red Cross – Emergency shelter program, homeless prevention services, housing assistance, Friendship Center, food pantry and case management Shelter Program & Food Pantry – 717 W. Court St. Ithaca, NY 14850 Phone: (607) 273-9177 Friendship Center - 617 W. State. St. Ithaca, NY 14850 Phone: (607) 273-6684 Case Management – 201 W. Clinton St., Ithaca, NY 14850 Phone: (607) 273-1900 Fax: (607) 273-7146

Samaritan Center

324 W. Buffalo St., Ithaca, NY 14850

Referrals and assistance clothing, personal needs products, prescriptions, security deposits, utilities, transportation and emergency financial support to low income residents with urgent needs in Ithaca and at sites in Dryden, Enfield, Danby and Caroline. Site for Child Health Plus, Family Health Plus applications and Food Stamps screenings in Tompkins County. Phone: (607) 272-5062 Fax: (607) 272-4427

211 Information and Referral – Community Services

Senior Services

Tompkins County Office for the Aging, 320 N. Tioga St., Ithaca, NY 14850 Information and referral Phone: (607) 274-5482 Fax: (607) 274-5495

<u>SPCA of Tompkins County</u> – provides animal shelter and care for homeless animals

640 Hanshaw Rd., Ithaca, NY 14850 Phone: (607) 257-1822 Tompkins County Rabies Clinics Short-term respite for pets Low cost spaying and neutering

Fax: (607) 257-5470

Other Animal Resources

Friendship Center - 617 W. State St., Ithaca, NY 14850, Phone: (607)273-6684 Free pet food, cat litter on Fridays

Southside Community Center – 305 S. Plain St., Ithaca, NY 14850, Phone: (607) 273-4190 Low cost clinics for veterinary care, vaccinations and exams (no spaying/neutering)

Zoning, Building inspectors

ig, building inspectors	
Village of Cayuga Heights Code Officer	257-5536
Village of Dryden Zoning Officer	844-8888
Village of Freeville Zoning Officer	844-8301
Village of Groton Zoning Officer	898-3966
Village of Lansing Zoning Officer	257-8363
Village of Trumansburg Zoning Officer	387-6501
Building/Fire Inspecto	or 387-6501
Town of Caroline Building Code Enforcer	539-6700
Town of Danby Code Enforcement Officer	277-0799
Town of Dryden Zoning/Code Enforcement Office	er 844-8888
Town of Enfield Code Enforcement Officer	273-8256
Town of Groton Zoning Officer	898-4428
Town of Ithaca Code Enforcement Officer	273-1721
Town of Lansing Code Enforcement Officer	533-7054
Town of Newfield Fire and Building Code Officer	564-9981
Town of Ulysses Zoning Officer	387-9778
City of Ithaca Zoning Officer/Building Commission	oner 274-6508

Legal Services

Neighborhood Legal Services – 215 N. Cayuga St., The Dewitt Building, Ithaca, NY 14850 Provides legal assistance to low-income individuals in civil cases only. Legal services are available for issues involving housing (including evictions), public benefits, Social Security and SSI, unemployment Phone: (607) 273-3666 fax: (607) 273-5521

Professional Organizers

less stuff. more life.

Lisa Margosian, Professional Organizer Phone: (607) 589-7252 email: <u>lmargosian@gmail.com</u> Partnering with clients to simplify, streamline, and transform spaces, systems, and habits to create greater satisfaction and increased productivity at home and at work. *Experienced with cluttering, hoarding, and chronic disorganization.*

Clear the Way Organizing

Linda Story, Professional Organizer PO Box 4185, Ithaca, New York, 14852 Phone: (607) 592-0914 www.cleartheway.com

email: <u>linda@cleartheway.com</u>

Books on Hoarding

Compulsive Hoarding and Acquiring: Therapist Guide (Treatments That Work) Gail Steketee and Randy Frost Oxford University Press (2006)

Compulsive Hoarding and Acquiring: Workbook (Treatments That Work) Gail Steketee and Randy Frost Oxford University Press (2006)

Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding David F. Tolin, Randy O. Frost, Gail Steketee Oxford University Press (2008)

Overcoming Compulsive Hoarding: Why You Save & How You Can Stop Fugen Neziroglu, Jerome Bubrick, Jose A. Yaryura-Tobias New Harbinger Publications (2004)

Digging Out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring Michael Tompkins, Tamara Hartl New Harbinger Press (2009)

Stuff: Compulsive Hoarding and the Meaning of Things Randy Frost and Gail Steketee Houghton Mifflin Harcourt (2010)

Books on Organizing and Chronic Disorganization

ADD-Friendly Ways to Organize Your Life Judith Kolberg and Kathleen Nadeau

Routledge (2002)

Conquering Chronic Disorganization Judith Kolberg Squall Press (2006)

SHED Your Stuff, Change Your Life

Julia Morgenstern Fireside (2009)

Making Peace with the Things in Your Life Cindy Glovinsky St. Martins Griffin (2002)

It's All Too Much Peter Walsh Free Press (2007)

It's All Too Much Workbook Peter Walsh Free Press (2009)

Books on Downsizing and Organizing Seniors

Don't Toss My Memories in the Trash Vickie Dellaquila Mountain Publishing (2007)

Web Resources

OC Foundation Hoarding Website http://www.ocfoundation.org/hoarding/ Includes compulsive hoarding rating scale

Understanding Compulsive Hoarding http://understanding_ocd.tripod.com/index_hoarding.html

National Study Group on Chronic Disorganization http://www.nsgcd.org/ Includes clutter hoarding scale

Cornell University Medical School - Environmental Geriatrics http://www.cornellaging.com/gem/hoarding_index.html Includes hoarding assessment scale

Clutterers Anonymous

www.clutterersanonymous.net

12-step fellowship of individuals who share experience, strength and hope with each other in order to solve their common problems with clutter and help others recover.

Clutterless Recovery Groups, Inc.

www.clutterless.org

Support for those who find it difficult to discard unwanted possessions, using psychological principles to change behavior newsletters, literature, information, referrals, conferences, pen pals and group meetings.

Children of Compulsive Hoarders http://www.childrenofhoarders.com/