

Hoarding Task Force Guide

Created by the Hoarding Task Force 2024

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Acknowledgements

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City of Des Plaines Health and Human Services
City of Evanston
CJE SeniorLife - Care Management
Code Enforcement Morton Grove
Cook County Sheriff's Office
Josselyn Center

Metropolitan Family Services - APS
Northbrook Police Department
North Shore Senior Center - APS
Village of Morton Grove
Village of Lincolnwood
Village of Skokie

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For more information about this Guide or the Skokie Hoarding Task Force, please contact: CJE SeniorLife Care Management at 773-508-1310 or 773-508-1311.

For specific resource information and community agency contact information, see pages 9-11.

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This Hoarding Task Force Guide is designed for use by professionals and consumers who may encounter hoarding.

Our hope is that this Guide will give individuals an increased understanding of the complexities of hoarding behavior, and valuable information on the assistance available locally. If you have picked up this Guide and are looking for assistance, we urge you to call one of the community agencies listed in this Resource Guide. For those who are looking for a deeper understanding of the phenomena of hoarding, there is a bibliography at the end of this Guide, as well as a list of current web resources.

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Hoarding 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. Hoarding can result in a high level of disorganization and clutter that affects a person's ability to function in their home. 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 as:

- 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:*
 - 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 | ➤ Mail | ➤ Papers |
| ➤ Clothing | ➤ Notes and lists | ➤ Animals |
| ➤ Containers | ➤ Personal items | |

Some Basic Information about Hoarding Disorder

Hoarding behavior will vary from case to case, but the following general facts may be useful to individuals who come in contact with those who hoard:

- Hoarding affects individuals across all socio-economic and ethnic groups
- Hoarding is a neurological disorder, *not* a result of being lazy or 'weak-willed'
- Hoarding can be resistant to traditional talk therapy and medication
- Typically, hoarding begins with clutter and difficulty discarding items, but progresses over time to become unmanageable and overwhelming
- Those experiencing 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
- Individuals who hoard are often depressed, anxious, and experience social phobias
- Severity often increases with age
- Fifty percent of individuals who hoard grow up with a hoarding family member
- Stressful life events such as unresolved grief due to the death of a loved one, divorce, domestic violence, eviction, etc., can lead to hoarding
- Those experiencing hoarding tend to be socially isolated, withdrawn

Definition

Hoarding currently has its own disorder in DSM-5 (Diagnostic and Statistical Manual of Mental Disorders), separate from Obsessive Compulsive Disorder (OCD). The DSM-5 diagnostic criteria for hoarding disorder are:

- Persistent difficulty discarding or parting with possessions, regardless of their actual value.
- This difficulty is due to a perceived need to save the items and distress associated with discarding them.

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- The symptoms result in the accumulation of possessions that congest and clutter active living areas and substantially compromise their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g. family members, cleaners, authorities).
- The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment for self and others).
- The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi Syndrome).
- The hoarding is not better explained by the symptoms of another mental disorder (e.g. obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Hoarding behavior may be a feature of a mental illness or be exacerbated by an underlying condition. Professionals working with those who experience hoarding disorder should keep in mind the possibility that these other issues may interfere with assistance and treatment.

Possible Co-Existing Mental Illnesses

People with Hoarding Disorders may also have the following mental health disorders:

- Major Depression
- Social Phobia
- Generalized Anxiety Disorder
- Attention Deficit Hyperactivity Disorder
- Obsessive Compulsive Disorder
- Specific Phobia
- Post-Traumatic Stress Disorder (PTSD)
- Dysthymia
- Panic

The following lists the most common feelings expressed by those who experience hoarding:

- Fear of losing important items that might be needed later
- Distorted beliefs about the importance and value of possessions
- Excessive emotional attachment to possessions -- individuals who hoard 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: Perfectionism, Indecisiveness, Procrastination, Avoidance and Attention

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Health, Safety and Other Risks of Hoarding

- Social Isolation
- Medication Mismanagement
- Dust/Insects
- Limited Mobility
- Increased risk of fall and injuries
- Emergency response personnel may not be able to navigate inside the home
- Inadequate cleaning, mold
- Inability to prepare food, higher risk of food contamination
- Rotting food and lots of paper can lead to rodent infestation
- Bills/property taxes not being paid or taxes not filed
- Lack of bathing facilities, resulting in poor hygiene
- Fire hazards caused by blocked exits and large amounts of flammable items
- Structural Damage causing building condemnation or infestations affecting whole buildings
- Danger of being trapped
- Possibility of eviction
- In-home service providers may be unable to access home to provide care.

Risks Associated with Animal Hoarding

- The hoarding of animals carries the risk of disease and parasites
- Animal neglect and death
- Denial about the lack of care that the animals receive and also about the deteriorating condition of the animals and their environment

What Should Professionals Know About Those Who Hoard?

This list is not all-inclusive, but these guidelines are offered by peer professionals who have worked with people who hoard.

- Individuals may recognize that they need help but are unable to move at the same pace as service providers to clean the home and reduce the number of possessions.
- Individuals benefit from clarity about who you are, why you are there, and what is expected of them.
- Individuals benefit from having a clear description of what needs to be done to solve the immediate problem, such as avoiding eviction or loss of housing.
- Individuals benefit from help in setting specific, achievable, short-term goals.
- Individuals usually believe that every item they possess has meaning. It is important to be empathetic.
- Individuals may experience extreme stress when trying to remove items from the home.
- Individuals benefit from help in finding creative solutions to reduce their possessions.
- Individuals benefit from reassurance that it will be possible to replace an item or find information again at a future date, if they feel they might need it.
- Individuals benefit from feeling that the removed items are being put to good use.

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Considerations for Loved Ones

- Chronic Illness - Do they have any conditions that limit their ability to function? Do they report health concerns that aren't being addressed?
- Medications – Are they properly taking medications?
- Memory Loss – Are memory issues affecting their ability to function?
- Mobility – Can they move safely in the home?
- Nutrition – Can they shop and prepare food?
- Physician – When is the last time they have seen a primary care doctor or a needed specialist?
- Financial – Are they current on their bill payments? Credit card debt?

If an individual's basic needs are not being met, please refer to the appropriate professional (see pages 9-10) or call 911.

Can Hoarding be Treated?

There is help and hope for those who experience 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 experience, and their loved ones should understand that there are no quick, easy answers.

Hoarding Disorder 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 individual's behaviors, not just understanding the motivations. CBT challenges the thoughts and beliefs about the individual'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.
- For some, group treatment can be more effective than individual treatment.
- Effective treatment involves education and intervention that targets specific aspects of hoarding.
- The individual works to reduce their possessions themselves usually with the assistance of a professional or family member. This process may begin with visualizing discarding items, gradually working toward discarding items first with support, then on their own. The individual's tolerance for this will likely start low and will build gradually. This can be a slow, lengthy process.
- It is counterproductive to treatment for others to come into the home and "clean it out" without the permission and/or involvement of the individual. The individual'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 significant emotional reactions. If this type of forced intervention is deemed medically or legally necessary, mental health personnel should be on hand when the individual re-enters the home, and available for ongoing support.
- Individuals will work with the therapist to develop strategies for preventing relapses into old behaviors.

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Relevant Fire and Building Code Violations

Major violations may 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

- Nonfunctional stove*
- Nonfunctional refrigerator*
- Nonfunctional sink*
- Nonfunctional appliances*

Bath

- Nonfunctional sink*
- Nonfunctional bathtub*
- Nonfunctional water heater or central water-heating equipment*

General

- Obstructed exits
- Unsanitary exterior or interior conditions (i.e. excessive accumulation of garbage)
- No potable water for drinking or sanitary purposes
- Existing sewage backup/water damage
- 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

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

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Assess Support System Status

- Who does the individual rely upon on a day-to-day basis?
- Do they have a caseworker who assists them?
- When was the last time they saw a mental health professional?
- Are family and friend support available to assist the individual?
- What is their relationship with the landlord?
- If the individual is willing to allow contact with support system, obtain contact information.
 - With permission, call the supports and determine how the supports can address the issues recognized through the assessment.

Hoarding – When to refer to Adult Protective Services

A report to Adult Protective Services (APS) should be made when the hoarding behavior is causing an adult with a disability or an older adult (age 60+) to not be able to meet or have their *essential* care needs met that *substantially* threaten their own health, including but not limited to providing food, clothing, shelter, and health care; and obtaining goods and services necessary to maintain physical health, mental health, emotional well-being and general safety. This would include but is not limited to hoarding caused by or not prevented by a person the eligible adult has a relationship with and cases of self-neglect. The requirements for a referral for passive neglect can be less stringent than for self-neglect and can include failing to understand the eligible adult's needs and awareness of services to meet the needs. It is always useful to call (without giving the individual's name) if you are unsure if the situation meets the program requirements.

Some Indicators of Passive or Self Neglect

- No food/spoiled food/inadequate food
- Individual appearing malnourished/dehydrated
- Health conditions not attended to appropriately
- Inability to prepare food
- Fleas/lice/cockroaches/bedbugs/mice/rats/vermin
- Hoarding of Animals
- Excessive Clutter/Hoarding Possessions
- Home Extremely Dirty/Garbage Piled Up
- Offensive Odors in home or on person
- Home in Disrepair/Unsanitary
- Inadequate Heat/Water/Plumbing/Electricity
- No appliances or non-functioning appliances
- Financial Mismanagement due to inability to pay bills
- Untreated injuries
- Not taking prescribed medications
- Unable to respond to emergencies

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To refer to Adult Protective Services call:

All reporters of neglect, abuse, or exploitation to APS can be anonymous and kept confidential.

Metropolitan Family Services, APS Hotline - 312-986-4332 (Monday-Friday, 8:30am-5pm)

- Skokie Office - 847-425-7500
- Covers Glenview (southeast segment), Golf, Lincolnwood, Morton Grove (east three-quarters), Niles (southeast half), Skokie, and Evanston

North Shore Senior Center - 847-784-6000 (Monday-Friday, 9am-5pm)

- Covers Des Plaines, and Maine, New Trier and Northfield townships

Illinois Department on Aging, 24-hour hotline - 866-800-1409

Emergency Crisis Response Options

- Individual is overtly psychotic or appears to be a danger to self or others – call 911
- If not imminent risk of harm, call 988 for the National Mental Health Crisis hotline

Living Conditions Considerations

- Is a minor at risk in the home? Call Dept of Child and Family Services at 800-252-2873
- Is an eviction or foreclosure pending or is the individual at risk of losing their housing and need legal services? Call Legal Assistance Foundation at 312-341-1070 or Center for Disability and Elder Law at 312-376-1880
- Are an individual's basic needs not being met, including not paying rent?
Is there an infestation of insects, rodents, or other unhealthy living conditions?

Animal Hoarding – When to refer to Animal Control

- How many animals are involved?
- Where are the animals located?
- What conditions are the animals being kept in? Do they 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?

For Animal Control or concerns about neglected pets call the local municipality and ask for Animal Control, the Police Department, or contact the Anti-Cruelty Society at 312-644-8338.

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Animal Hoarding Resources

- Red Door Animal Shelter - 773-764-2242, <https://reddoorshelter.org/>
- PAWS Chicago Crisis Foster Care - <https://www.pawschicago.org/>
- Wonder Bunny Rabbit Rescue - 708-280-4301
- Happy Haven Small Animal Rescue - <https://www.hhsar.org/>
- The House Rabbit Society - <https://rabbit.org/>

General Numbers to Call

For General Care Management and other questions for Adults aged 60 or older call:

- CJE SeniorLife at 773-508-1000
- North Shore Senior Center at 847-864-3721

For General Case Management and other questions for Adults with Disabilities call

- IL DHS - Department of Rehabilitation Services at 877-581-3690
 - Or submit online referral at <https://wr.dhs.illinois.gov/wrpublic/wr/dynamic/referral.jsf>
- Community Alternatives Unlimited at 847-867-4000

Other Relevant Organizations

- International OCD Foundation at 617-973-5801 or <https://iocdf.org/>
- National Association of Productivity & Organizing Professionals at 651-288-3433 or <https://www.napo.net/>
- Institute for the Challenging Disorganization at 800-674-7818 or www.challengingdisorganization.org

Cleanout Companies

Services have been provided by these vendors by individuals who needed cleanouts due to hoarding. We are not endorsing, recommending, nor do we have any contractual relationships with the following companies.

- Blu Commercial Cleaning - 773-628-7505, <https://blucleaning.com/services/residential-carpet-cleaning/>
- Dawn Metzler - Service Master, Elk Grove - 708-514-7350
- Dawson Relocation Services - 847-922-6143, <https://dawsonrelocation.com/>
- Junk Luggers - 847-250-0178, <https://www.junkluggers.com/chicago-nw-suburbs/>
- Nancy Katz Clutter Consultant - 847-254-8888, www.nancybkatz.com
- Red's Hauling Service - 773-616-0979, <https://redshaulingservice.com/>

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Community Contacts

City of Des Plaines Human Services - Community & Police Social Worker
847-391-5480
1418 Miner Street, Des Plaines, IL 60016

City of Evanston
847-448-431
health@cityofevanston.org

CJE SeniorLife – Care Management
773-508-1310
3003 W Touhy Ave, Chicago IL 60645

Cook County Sheriff - Senior Services
Kevin Kelly
708-865-7333
kevin.kelly@ccsheriff.org

Josselyn Center
847-441-5600

Metropolitan Family Services - Skokie
847-425-7500

North Shore Senior Center
847-784-6000

Village of Lincolnwood – Social Worker
847-745-4755

Village of Morton Grove - Social Worker
847-663-3072
Monday-Friday, 8am-4pm

Village of Skokie Health and Human Services
847-933-8208
5127 Oakton St, Skokie, IL 60077

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Assessments/Screenings

- HOMES – Multidisciplinary Hoarding Risk Assessment
- Clutter Hoarding Scale (C-HS)
- Clutter Image Rating Scale

Books and Articles on Hoarding

Animal Hoarding: Structuring Interdisciplinary Responses to Help People, Animal and Communities at Risk, 2006, Edited by G. Patronek, L. Loar and J. Nathanson, Tufts University

Bratiotis, C., Schmalisch, C.S. & Steketee, G. (2011). The Hoarding Handbook: A Guide for Human Service Professionals. New York, NY: Oxford University Press

Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding
David F. Tolin, Randy O. Frost, Gail Steketee Oxford University Press (2007)

Compulsive Hoarding and Acquiring: Therapist Guide (Treatments That Work) Gail Steketee and Randy Frost, Oxford University Press (2013)

Compulsive Hoarding and Acquiring; Workbook (Treatments that Work), 2006, Gail Steketee, Randy Frost, Oxford University Press

Digging Out: Helping Your Loved One Manage Clutter, Hoarding, and Compulsive Acquiring, 2009, Michael A. Tompkins and Tamara Harti, Harbinger Press

Hoarding Disorder: The Top Ten Problems and The Elephant in the Room, Joseph Dobrian, Journal of Property Management.

Hoarder Homes: Piles of Hazards for Firefighters, Ryan Pennington, chamberofhoarders.com.

Muroff, J., Underwood, P., Steketee, G. (2014). Group Treatment for Hoarding Disorder: Therapist Guide (Treatments that Work). New York: Oxford University Press.

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

Step Inside the Real World of Compulsive Hoarders, February 25, 2013, Ferris Jabr, Scientific American.

Stuff: Compulsive Hoarding and the Meaning of Things, 2011, Gail Steketee, Randy Frost, Mariner Books

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The hoarder in you: how to live a happier, healthier, uncluttered life, 2011, Robin Zasio, Rodale Books

Treatment for Hoarding Disorder: Therapist Guide (Treatments that Work), 2013, Gail Steketee, Oxford University Press

Why Do You Hoard, May 1, 2013, Bonnie Tsui, Pacific Standard.

Web Resources

OC Foundation Hoarding Website (Includes compulsive hoarding rating scale)

<https://hoarding.iocdf.org/>

Children of Compulsive Hoarders www.childrenofhoarders.com

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

International OCD Foundation www.iocdf.org

National Association for Professional Organizers www.napo.net

Institute for the Challenging Disorganization www.challengingdisorganization.org



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