

Understanding and Working with People with Hoarding Disorder ("HD")

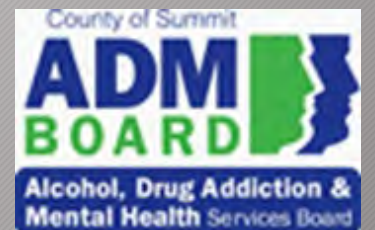
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Co-Chair, Summit County Ohio Hoarding Task Force

2023 Portage County Substance Abuse and Mental Health Conference

NEOMED, Rootstown, Ohio

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Special Thanks

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Training Goals

- Participants will learn how to differentiate between Collecting, Clutter and Hoarding Disorder (“HD”)
- Participants will learn diagnostic criterion for HD, assessment tools and treatment options
- Participants will learn the value of a Harm Reduction approach in working with challenging hoarding cases
- Participants will learn about resources for persons with HD

Who were Homer Lusk Collyer (1881-1947)
and Langley Wakeman Collyer (1885-1947)?



BRIEF HISTORY

• HOMER	LANGLEY
• Admitted to College of NY City, age 14	Studied engineering and chemistry at Columbia
Degree in Admiralty Law - Columbia	Concert pianist-Carnegie Hall
Work: Lawyer	Work: Piano Dealer
1933 lost eyesight (hemorrhages)	1933 Quit work to take care of Homer

The Collyer Brothers: Back story

6

- Accomplished parents (MD and Opera Singer)
- Parents died, six years apart, prior to Homer's stroke in 1932
- Remained in the parents' brownstone
- Acquired parents' possessions
- Increasingly shut off from neighbors
- Eccentricities and hoarding began
- Both refused doctors
- House break-ins; Langley traps set and windows boarded
- Homer's diet: 100 oranges/week, black bread and peanut butter
- Utilities and water shut off

March 21, 1947 Police call well check, 2078 5th Ave., Harlem, NY



The Collyer Brothers: Homer and Langley, NYC

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- Police arrived, dug for 5 hours, discovered Homer's dead body
- Floor to ceiling stuff.
- Massive, multi-state manhunt for Langley, presumed killer
- April 8, Langley's body found inside 2 ft wide tunnel, 10 ft from Homer
- Langley died 2 wks before Homer
- Homer inadvertently killed by one of Langley's traps

There was a LOT of Stuff

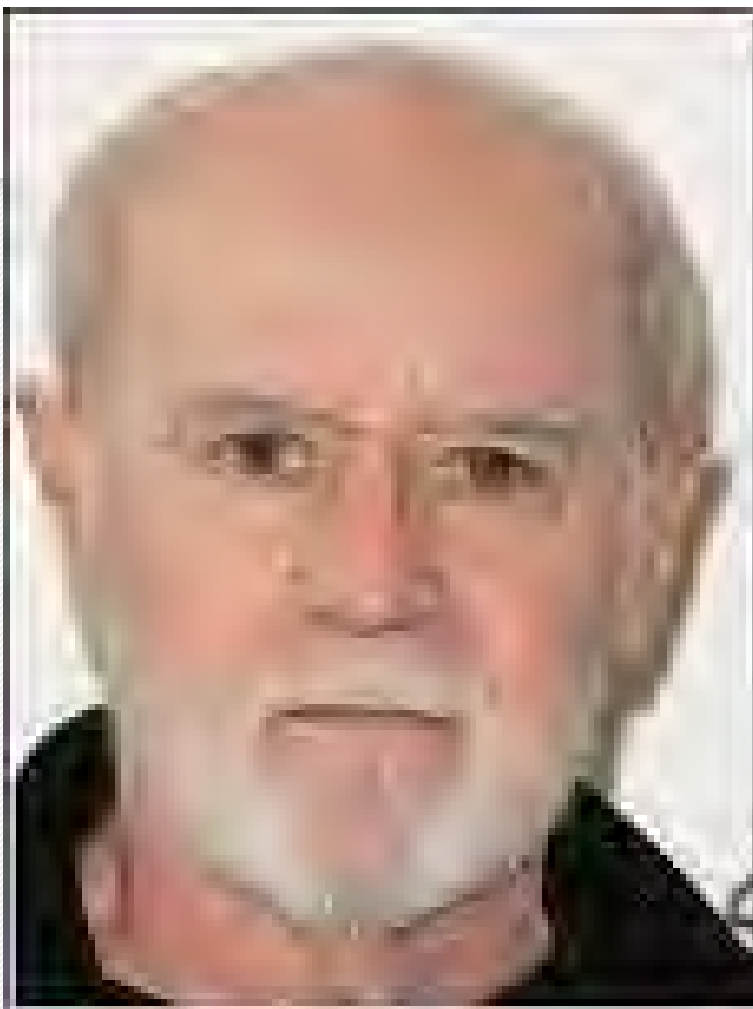
120 TONS OF STUFF

Let's talk about STUFF!



Is it hoarding or clutter or collecting?





A house is just a place to keep your stuff while you go out and get more stuff.

— George Costin —

AZ QUOTES

The Mind of a Collector

Source: [Psychologytoday.com/us/blog/the-mind-collector](https://psychologytoday.com/us/blog/the-mind-collector)

- “Adults Who Collect Dolls: Not Just Fun But Also Therapeutic”
- “Record Collectors: Unique Characteristics or Not?”
- “Collectomania: The Motivations Behind a Collector’s Passion”

Americans like to invent and like to buy!!

- In the history of our country, **it's never been easier to buy** (in person, online, by phone)
- We're inundated with messages to buy by advertisers- everywhere
- We have a "competitive consumption" culture (peers, family, neighbors). Self-esteem tied to owning objects.
- Ref: Sociologist Juliet Schor, [The Overspent American: Why We Want What We Don't Need](#)

Collecting vs. Hoarding

COLLECTING

- **Goal oriented**: budgeted time and money
- **Safe location**, damage awareness
- **Pride**: **showing off collection**
- Organized, good condition
- **Enjoy conversations about the collection**; may bring it up in conversation

HOARDING

- **Unplanned** over many years
- No \$ gain; \$ loss
- **Objects create clutter; possessions can't be found**
- Embarrassment, **shame**
- No organization, object damage
- Sad, depressed, guilt, frustration in not finding items

Characteristics of Collectors

- Collecting is a creative expression that brings joy to the collector
- Collectors like to control, organize, their environment
- About 25% of collectors do so for income/investment (art, coins, etc.)
- Collectors long for times gone by
- "The feeling felt and the emotion experienced is what makes life worth living". "It is the lifeline of altering what might be a hum-drum existence."

Signs of Hoarding

- Blocked/cluttered exits
- Impaired pathways, stairway ("goat paths")
- Difficulty discarding items
- Losing important items in clutter
- Duplicate items
- Non-working or non-functional appliances, utilities
- Piles of "free" items (pens, note pads, cups, etc.) from community fairs or from "trash day"
- Not inviting in family/friends because of shame or embarrassment

Hoarding or Squalor?

Hoarding

- Accumulation of possessions
- Some health hazards

Squalor

- Accumulation of possessions
- Almost always due to excessive hoarding, but sometimes due to disability alone
- Foul odor, rotten food, human or animal waste
- Significant safety issue
- Often older adults
- High fire risk (x8 fire load)

Fast Facts

- The Average American Home has 300,000 objects from paper clips to ironing boards.
- American children make of up 3.7% of the world's population but have 47% of all toys and children's books
- 1 out of 4 houses with 2 car garages can't fit a car because of too much stuff. - U.S. Dept of Energy
- The average American woman has 103 items of clothing, but considers 78% to be too tight, too loose or otherwise unwearable. -ClosetMaid study
- 1 in 10 Americans rent offsite storage

- Ref: Mary Macvean, 3/21/14, LATIMES.COM. "For many people, gathering possessions is just the stuff of life".
- Becomingminimalist.com

Fast Facts

- Onset of hoarding behavior age 15-19 for most (Mayo Clinic)
- Children who hoard often have a parent who hoards
- About 50% of people who hoard have a relative who hoards
- Severity of hoarding increases with each decade of life
- Early intervention (teen and early, mid-adult) is ideal
- Hoarders first diagnosed in their 60's likely have 40 year old acquisition and saving habits
- Barriers to home cleanouts: physical disability, advanced age, costs (\$10k - \$20 K possible), social isolation, enough trained professionals, readiness for change

DSM-5 Criteria for Hoarding Disorder (F42.3) (partial)

- A. The **persistent** difficulty of discarding or parting with possessions, **regardless of their actual value**
- B. The difficulty is the result of a **perceived need** to save the items and **distress** associated with discarding them
- C. Hoarding behavior results in the **accumulation of possessions** that **congest and clutter active living areas** and **substantially compromises their intended use and potentially impacts safety**

DSM-5 Criteria, cont.

- D. 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

Areas that may be affected include:

- **Getting to work**
- **Socializing and maintaining friendships**
- **Creating economic hardship** because of needed renovations and cleanup costs

ANOSOGNOSIA

- “Anosognosia is a neurological condition in which the patient is unaware of their neurological deficit or psychiatric condition”.

- National Institute of Health

About 50% of people w HD or schizophrenia have anosognosia

“Without awareness of the illness, refusing treatment appears rational, no matter how clear the need for treatment might be to others” - Treatment Advocacy Center

What causes hoarding?



Hartford Hospital Study, 2012, Hartford, CT

Neural Mechanisms of Decision Making in Hoarding Disorder, David Tolin, M. Stevens, A. Villavicencio. Archives of General Psychiatry, 2012

- 107 subjects, 3 groups
- Piles of 2 y.o. junk mail/newspapers
- Functional MRI
- Scanned photo, “yours”, “ours”
- Save or shred? 6 seconds
- Hoarders kept significantly more of their junk mail
- Low brain activity when shown others’ items
- High brain activity (insula) when shredding own items



Brain structures that may impact hoarding behavior

Anterior Cingulate Cortex:

- Motivation
- Decision making
- Cost-Benefit calculation
- Fundamental Cognitive Processes

Insula Cortex:

- Processing emotions (anger, sadness, disgust, fear, anxiety)

Hoarders Have Unique Cognitive Processes

- Highly creative; artistic, find beauty easily in objects
- Attention deficit; lack of focus
- Categorization- more piles, more anxiety w sorting
- Memory & recall (keep things in sight)
- Processing speed slower
- Decision making slowed by perfectionism



Psychological Contributors to Hoarding

- Other conditions complicate treatment (depression and anxiety: 75%)
- Impaired problem-solving abilities
- Often have unhelpful thoughts (e.g., “Why bother? I’ll never make progress.” or minimize, “It’s really not that bad”)
- Strong emotional attachment to objects. Loss of personal property = loss of identity/security

For those with HD...

ACQUISITION provides:

- A rush, boost, high
- A sense of satisfaction, victory
- A sense of identity (I am what I own)

SAVING/HOLDING ON prevents:

- Feelings of regret, remorse, doubt
- Guilt from passing up a “good deal”
- A sense of loss & vulnerability

SOCIAL Contributors to Hoarding

- Learned hoarding behavior from (hoarded) childhood environment
- Environmental trauma often triggers increase in hoarding behavior (childhood trauma increases risk for developing HD)
- U.S. consumer culture encourages purchasing and excessive purchasing (BOGO)



Consumer-Oriented Culture

- Retail stores: *Sales! Coupons! BOGO!*
- *Too good a bargain to pass up!*
- Garage sales, auctions, AMAZON
- We're inundated with purchasing opportunities



How many Starbucks?

- 15,000 (2023)
- 1984- 6,600 Self Storage Buildings
- 2022- 50,000 Self-Storage Buildings



Who Hoards?

- About 4% of the general population have significant hoarding struggles (Portage County = 6,500)
- Equal frequency among genders
- All socio-economic categories, races, cultures
- Females typically live longer and are more likely to seek help

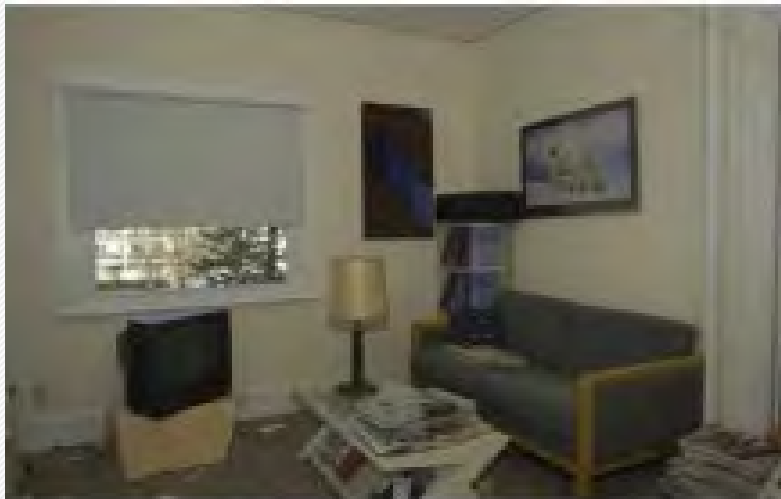




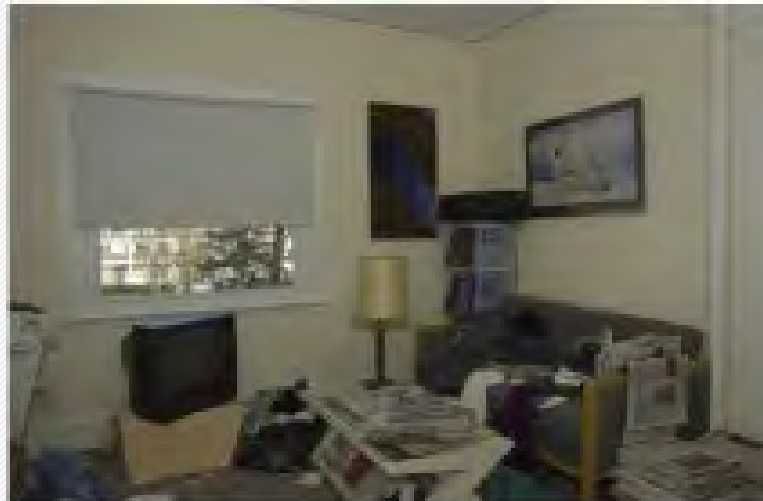
Assessment of HD

- Trained Mental Health Professionals can differentiate between collecting, clutter, hoarding and squalor.
- Ideal training for MH Professionals: cognitive behavioral therapy, motivational interviewing, stages of change, professional trainings
- MENTAL HEALTH AND SUD AGENCIES LIKELY HAVE UNDIAGNOSED, UNTREATED CLIENTS WITH HD ON THEIR CASELOADS
- International OCD Foundation has free, downloadable assessment tools (IOCDF)

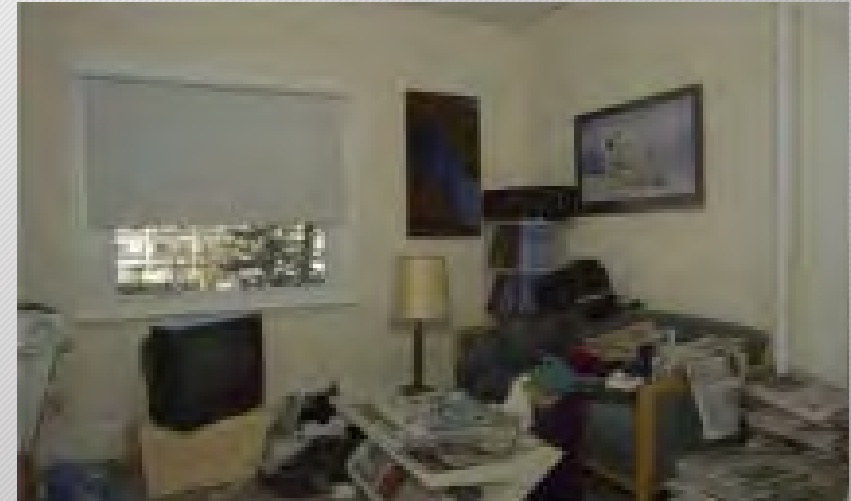
Clutter Image Rating Scale: Living Room



1



2



3

Clutter Image Rating Scale: Living Room



4



5



6

Clutter Image Rating Scale: Living Room



7



8



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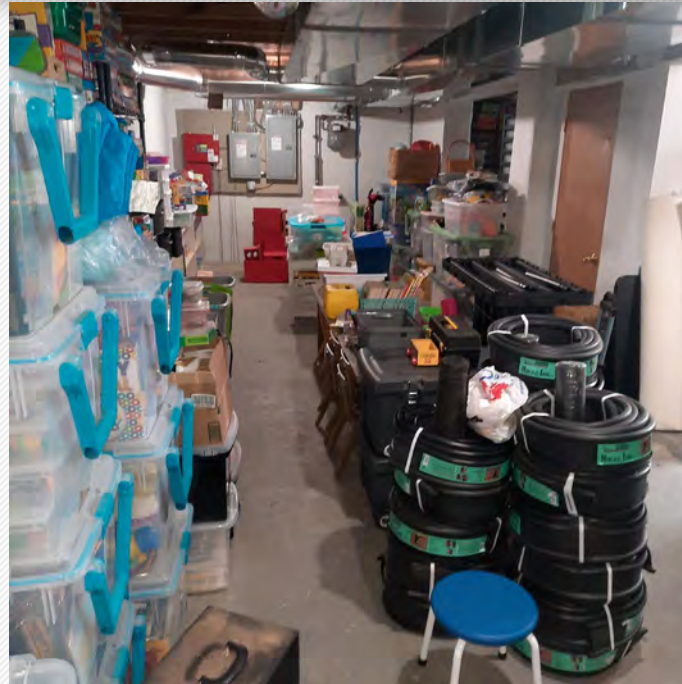
Hoarding Rating Scale*

Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?

0	1	2	3	4	5	6	7	8	9	10
Not at all		Mild	Moderate		Severe		Extremely Difficult			

*Philadelphia Hoarding Task Force - Assessment Tools

Why Declutter?



- Improves physical health
- Lowers stress
- Improves sleep
- Increases productivity
- Saves time and money
- Health and safety
- Feelings of accomplishment

Where to start

- Have your “tools” in a container
- Label boxes/bags for
 1. Trash
 2. Recycling
 3. Donate
 4. Give away to family & friends
 5. I don't know
 6. Needs cleaned
- Set a table up or use a sheet to cover a large surface for sorting
- Prioritize. Tackle one area at a time.
- Start with the floor. Sorting as you go
- It's easiest to start with clothing, expired food, large furniture, or you may path.



Strategies for helping someone w HD

- Always shop with a “helper”
- Go on non-acquiring trips
- Acquire 5 items, return 4
- Use a small basket vs a big cart
- Stick to a shopping list
- Stick to a budget
- Practice making small, short shopping trips
- Non-acquiring trips (5 min, then 10, etc)
- 15 minutes to select 1 Item to give away, repeat
- Decrease to 10 minutes
- Change to throwing away
- Focus on doors, floors, kitchen. bathroom
- Functional smoke detectors?
- Sell, give away to someone in need, trash, keep

General Goals for Client

- Develop a trusting relationship with a kind, sincere person who is non-threatening
- Work toward a hazard free home **daily**
- Improve decision-making abilities
- Increase distress tolerance
- Increase/establish living space
- Increase appropriate use of living space

Approaches for those working w people with HD (diagnosed, or not)

- Be kind. Judgment Free.
- Become an expert on HD
- Become familiar with Stages of Change and Motivational Interviewing skills
- Establish rapport- help the client with the problem as they see it
- Encourage therapy by a licensed MH clinician with HD training





TREATMENT OPTIONS

Some Treatment Tools and Therapies

- Cognitive Behavioral Therapy
- Motivational Interviewing
- Exposure Therapy
- Skills Training
- Group/Family Therapy
- Medication (depression, anxiety, ADHD)
- Case management
- Self help (Buried in Treasures)

▶ Harm Reduction

Harm Reduction Approach/Mindset



- Focus on acquisition if that's still an issue (non-purchase "shopping")
- Not necessary to completely clear out the home
- **Small, achievable goals** that focus on safety and **increased accessibility**, such as
 - Working smoke detectors
 - Clear hallways, stairs, doors, and windows
 - Working appliances
 - No waste, garbage, rotted food

Cognitive Behavioral Therapy for Hoarding Disorder

- Most effective individual treatment
- One model: 26+ visits over 9-12 months
- Home and office visits
- Goal
 - Improve positive behaviors by addressing dysfunctional thoughts and feelings that are obstacles to change



Motivational Interviewing (MI) throughout treatment

- Non-confrontational approach
- Helps the client connect their values, goals and behavior
- “How would you like things to be different?”
- “It sounds like you would like be able to reach the sink easier but you’re not sure where to start?”
- Increase client’s confidence in their ability to change



Skills Training

Improve ATTENTION

Helpful strategies include:

- Use of a timer
- Having another present to gently redirect attention to task
- Leave only immediate working area visible to decrease distractibility (e.g., using tarp, sheet to cover other piles)

Improve CATEGORIZATION

- Tend to be visual/spatial organizers (multiple piles of items)
- Teach clients how to organize by categories and locations *they can remember*
 - Trash, sell, donate, keep
 - Teach logical, out of sight storage
 - O.H.I.O. Only handle it once

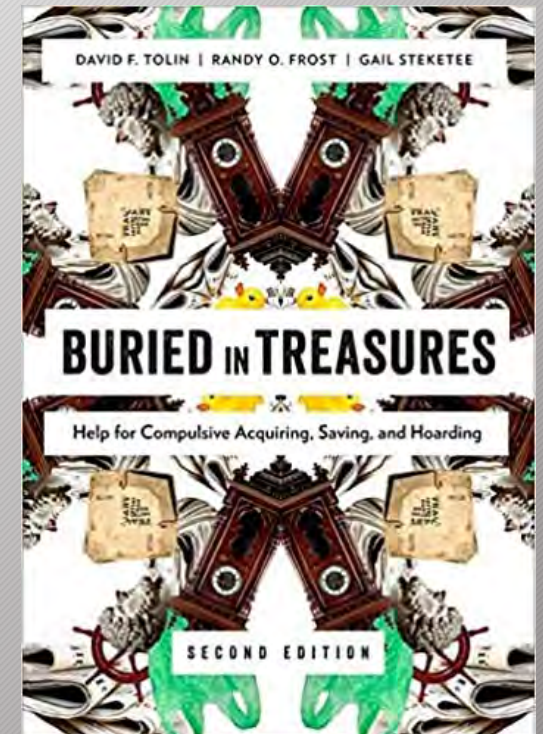
Improve DECISION MAKING

- Addresses perfectionism and fear of mistakes that impede decision making
- Help client identify distorted beliefs
- Normalize feeling of distress but help hoarder identify their rationale for making the change (to behave consistently with personal values)

Buried in Treasures Treatment Group

- Based upon the book, *Buried in Treasures*, by Steketee, Frost, & Tolin (2nd ed, 2013)
- 15 sessions over 20 weeks
- Peer-led
- Highly structured, step-by-step
- Addresses some of the biggest obstacles to treatment access
 - Lack of trained mental health professionals
 - Cost
 - FREE FACEBOOK Hoarding Disorder and Buried in Treasures Support Group

<https://www.facebook.com/groups/2173610616110515>



The Role of Helpers in the Treatment Process

- May be family, friend, peer, volunteers, professional
- Educated in hoarding disorder
- Emotional support; cheerleader
- Help client stay focused on tasks
- Help with hauling out discarded stuff
- Go with client on “window-shopping” non-acquiring trips (exposure activity)
- Only **help** with decisions; *this is not the helpers responsibility*
- Make check-up visits

Rules for All Helpers

- **DO NOT** sneak things out of the client's home—**EVER!!!**
- Do not argue
- Ask permission always before touching or moving possessions
- Learn client's rules and honor them
- Show empathy; this really isn't about "stuff"—it's about identity
- Watch your language (e.g., "junk", "trash")
- Take care of yourself
- **DO NOT** sneak things out of the client's home—**EVER!!!**

Resources for people with clutter/hoarding issues

- Call 2-1-1
- Clutterers Anonymous
- International OCD Foundation website
- Summit County ADM Hoarding Task Force (under community partnerships)
- Portage Path BH, CSS, Coleman Professional Services, Greenleaf
- Adult Protective Services (neglect or exploitation)
- 1-800-HOARDERS 24hr helpline
- <https://hoarders.com>
- <https://clutterhoardingcleanup.com>
- Address Our Mess website
- clutterhelp@admboard.org
- Get free home estimates
- Vantage Aging Chore Services
- Direction Home- RN in home assessments
- Blick Center- counseling/Case management

Resources on the Web

- Summit County Hoarding Task Force: <https://www.admboard.org/hoarding-task-force.aspx>
- Clutterers Anonymous: www.clutterersanonymous.net
- Messies Anonymous: www.messies.com
- Clutterless Recovery Groups, Inc.: www.clutterless.org
- Children of Hoarders: www.childrenofhoarders.com
- National Organization of Professional Organizers: www.napo.net
- National Study Group on Chronic Disorganization: www.nsgcd.org
- Hoarding of Animals Research Consortium (HARC): www.tufts.edu/vet/cfa/hoarding/index.html
- International Obsessive Compulsive Foundation: www.iocdf.org

Resources: Books

- Bratiotis, C. et al, (Spring 2016). *Beyond the Sensationalism: Professional Responses to Hoarding Disorder in the Omaha Community*. Univ of Nebraska, Grace Abbott School of Social Work.
- Bratiotis, C., Sorrentino-Schmalisch, C., and G. Steketee. (2011). *The Hoarding Handbook: A Guide For Human Service Professionals*. Oxford University Press.
- Frost, RO and G. Steketee. (2010). *Stuff: Compulsive Hoarding and The Meaning of Things*. Houghton Mifflin Harcourt Publishing Company.
- Pagano, Anne, (October 2, 2018). *Hoarding Disorder: A Collaborative Community Approach*. www.HoardingDisorderGroup.education
- Steketee, G., and RO Frost. (2007). *Compulsive Hoarding and Acquiring: A Therapist's Guide*. Oxford University Press.
- Steketee, G., and RO Frost. (2007). *Compulsive Hoarding and Acquiring: Workbook*. Oxford University Press.
- Tolin, DF, RO Frost, and G. Steketee. (2007). *Buried in Treasures: Help for Compulsive Acquiring, Saving, and Hoarding*. Oxford University Press.
- Tompkins, MA. (2014). *Clinician's Guide to Severe Hoarding: A Harm Reduction Approach*. Springer
- Tompkins, MA & T L Hartl. (2009). *Digging Out: Helping Your Loved One Manage Clutter, Hoarding, & Compulsive Acquiring*. New Harbinger Publications.

Some Summit County Resources

- **INFO:** ADM Board www.admboard.org > Community Partnerships > Hoarding Task Force
- **INFO:** 211 INFO LINE
- **Assessment:** Summit County Children Services, Adult Protective Services, SC Health Dept, City of Akron Housing, Fire Dept, City Building Inspector
- **Counseling:** Portage Path, Community Support Services, Blick Center, Greenleaf, Coleman Services
- **MINOR Cleanup:** Vantage Aging, Tri-County Independent Living Center and Direction Home Akron Canton Area Agency on Aging & Disabilities



Summit County Hoarding Task Force

- Approximately 21,000 people w diagnosable hoarding disorder (HD) in Summit County
- For most people w HD, behaviors start by age 15
- Task Force is composed of 30 community agencies and individuals
- Meet online monthly, 2nd Thursday, 8 a.m.
- We strongly advocate for education and counseling



Questions?

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