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## What You Need to Know When a Resident Hoards

### OVERVIEW

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According to the American Psychiatric Association, 2-6% of the U.S. population exhibit a hoarding disorder. This tendency doesn't suddenly disappear when a person enters a senior living community. So, if you have worked in eldercare for any length of time, you have likely encountered hoarding. But, what is hoarding and how does it differ from being a "pack rat?" This session will explore hoarding in senior living by first defining hoarding and identifying the types of hoarding behaviors.

This course will look at the scope of the issue in various levels of senior living (e.g., independent/assisted living, SNF, senior housing), reasons why individuals may hoard, health conditions that might lead to hoarding behavior, and the effects (physical, social, emotional) of hoarding behavior. Approaches and signs for recognizing hoarding behavior will be addressed. Finally, strategies to address hoarding in senior living will be offered including how to balance interventions with resident rights, standardized assessment to determine the severity of hoarding, the do's and don'ts of communicating with a hoarder and practices for supporting the hoarder toward a place of health and well-being. Additional evidence-based tips for supporting individuals who don't think they hoard and for living with someone who is hoarding will be offered. When dealing with a hoarder you need to make the most of your encounters. By learning a new way to break down the barriers of hoarders you can make a difference in their quality of life and teach them, their families, and staff how to help them understand it and help them.

**LEARNING OUTCOME AND OBJECTIVES:** Upon completion of this course, you should be able to:

- Describe the scope of hoarding in senior living and how it differs from collecting
- Identify signs of hoarding behaviors and their effects on health and wellbeing
- List strategies providers may use to address and reduce hoarding behavior in residents
- Identify verbal and non-verbal communication strategies to address hoarding and support the emotional wellbeing of hoarders

### INTRODUCTION

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Hoarding disorder is an ongoing difficulty throwing away or parting with possessions because you believe that you need to save them. You may experience distress at the thought of getting rid of the items. You gradually keep or gather a huge number of items, regardless of their actual value.

Hoarding often creates extremely cramped living conditions with only narrow pathways winding through stacks of clutter. Countertops, sinks, stoves, desks, stairways and all other surfaces are usually piled with stuff. You may not be able to use some areas for their intended purpose. For example, you may not be able to cook in the kitchen. When there's no more room inside your home, the clutter may spread to the garage, vehicles, yard and other storage areas.

Hoarding ranges from mild to severe. In some cases, hoarding may not have much impact on your life, while in other cases it seriously affects your daily functioning.

People with hoarding disorder may not see it as a problem, so getting them to take part in treatment can be challenging. It can be challenging for long-term care providers when residents amass large quantities of possessions. Facilities generally worry about hoarding when the number of belongings prohibits the resident or staff members from safely moving about their room or apartment. Other concerns include fire safety and the possibility of attracting vermin in spaces that are unable to be properly cleaned, as well as apprehension that a cluttered room will attract negative attention from state surveyors.

On the other hand, cleaning out a room against the will of a resident could be perceived as a violation of their right to “security of possessions.” Facilities often feel stuck between the proverbial rock and a hard place.

Firsthand observations:

- “The State is going to be here any minute,” the Director of Social Work told me, her voice rising a couple of octaves with panic, “We need you to tell Mrs. White that she’s got to get rid of all that junk.”
- Hoarder Number One, complaining bitterly about Hoarder Number Two: “Why are they telling me I need to throw away my things when she has even more stuff than I do? Her room is a mess! At least mine is organized. They just don’t bother her because she’s friends with the administrator.” (All accurate perceptions.)
- Comment from the maintenance guys to the hoarding resident after showing up at the door with cardboard boxes and a dolly: “We’re going to pack up your room for a few weeks until after the State visits, then we’ll bring it back.”
- Sitting with Ms. Rosario following an unannounced purge of her room while she was at dialysis: “How could they do this to me? I trusted them! That stuff was really important to me,” she said, referring to, among other things, an assortment of straws and every food tray slip she’d gotten since her arrival at the facility over a year ago.

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## WHAT IS HOARDING?

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Hoarding disorder, according to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-V) from the American Psychiatric Association is defined as “persistent difficulty discarding or parting with possessions, regardless of their actual value” which leads to a cluttered and frequently unsafe environment.

Hoarding has long been documented but has only been systematically studied just within the last decade. Hoarding Disorder was only added to the most recent DSM update in 2013, when the DSM-V was released. This is the extreme side of hoarding where it interferes with normal daily activities such as cooking, sleeping, moving through spaces, as well as relationships with family, friends, or loved ones. It can even become a health or safety hazard either because of restricted movement or as a result of the items themselves (possible decomposition or attracting critters, etc.).

Compulsive hoarding includes ALL three of the following:

1. A person collects and keeps a lot of items, even things that appear useless or of little value to most people, and
2. These items clutter the living spaces and keep the person from using their rooms as they were intended, and
3. These items cause distress or problems in day-to-day activities.

Hoarding goes far beyond being a messy person. Hoarding is having so many things that you cannot manage the clutter where you live and find it difficult or impossible to throw things away. It is excessive collection and retention of things until they interfere with day-to-day functions.

You might hoard because you feel a strong need to keep things. But, it's important to recognize that those who hoard are often distressed by the results of the behavior and its impact on their lives. Hoarders sometimes withdraw socially so that others don't see their cluttered homes. Others deny that it's a problem despite concerns voiced by friends and family members. For those with hoarding disorder, the compulsion to acquire belongings is out of their control and the thought of getting rid of the items causes distress.

While hoarding disorder is a mental health problem that a doctor can diagnose, it might also be a part of another mental or physical health problem.

If you hoard, you might:

- Feel the need to get more things, even if you have a lot already
- Have very strong positive feelings whenever you get more things
- Feel very upset or anxious at the thought of throwing or giving things away because of your emotional attachment to them
- Find it very hard to decide what to keep or get rid of
- Find it hard to organize your things
- Have so many things that you can't use parts of the place you live in – like not sleeping on the bed or using the sink
- Have lots of disagreements with the people close to you about your things
- Find it hard to pack for trips away, like a holiday – you might pack many more things than you really need, because you can't decide what's important

### **What does hoarding look like in senior living?**

Hoarding in long-term care usually expresses itself in one of three ways. The first is simply a refusal to get rid of things when they're no longer useful. Second, some residents ask relatives and friends to bring in lots of possessions they don't need. Finally, residents may shop (including online) for merchandise for which they have no need and no storage space.

There's another type of behavior we often see in nursing homes that some might consider hoarding. It happens when a resident lives with dementia. This involves a resident "shopping" in other residents' rooms and then hiding the collected items in their own room.

Important to note that hoarding may also be related to cognitive decline, dementia, Alzheimer's disease, depression, or Diogenes syndrome.

## SCOPE OF THE PROBLEM/STATISTICS

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A study by researchers at Johns Hopkins revealed that about 4% of the population shows hoarding behavior, but that percentage goes up to 6.2% in people over 55. Around 75% of individuals who have hoarding as a diagnosis also have a co-occurring mental health condition. The most common co-occurring disorders are major depressive disorder, social anxiety disorder/social phobia, and generalized anxiety disorder. Not only can hoarding cause physical danger as previously stated, it also increases the risk of falls in the home, creates hazardous or unsanitary conditions, and sometimes indicates the presence of Alzheimer's disease or other mental illness.

According to the American Psychiatric Association, 2-6% of the U.S. population exhibit a hoarding disorder. This tendency does not suddenly disappear when a person enters a senior living community. So, if you have worked in eldercare for any length of time, you have likely encountered hoarding.

### **What are the consequences of hoarding?**

Fortunately, with all the supervision available in senior living communities, we never reach the point of the hoarding catastrophes we see on TV. However, hoarding can still result in a variety of problems:

- Fire hazards
- Insects and rodents, especially with food hoarding
- Social isolation
- Increased risk of falls
- Financial problems
- Hazards for staff who enter to provide care
- Family conflicts
- Structural damage to the room or apartment
- Health risks (eating expired food, etc.)

## TYPES OF HOARDING BEHAVIOR

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### **Digital Hoarding**

Digital hoarding (also known as e-hoarding, e-clutter, data hoarding, digital pack-rattery or cyber hoarding) is defined by researchers as an emerging sub-type of hoarding disorder. Digital hoarding has been defined as "the accumulation of digital files to the point of loss of perspective, which eventually results in stress and disorganization." Digital hoarders often amass substantial volumes of digital content, struggling with the organization and disposal of their extensive files. Digital hoarding takes place in electronic environments where information is stored digitally. While psychological research into digital hoarding has received less attention than physical hoarding, psychologists are beginning to investigate and understand this emerging phenomenon.

Signs of digital hoarding:

1. You accumulate digital files easily, even if unimportant. This is likely to involve an overflowing inbox crammed with endless emails, accumulating folders of digital photos left largely untouched, or stockpiling unnecessary administrative files, all rationalized by the slim chance you may actually need them in the future.
2. You're reluctant to delete unused files. Once digital hoarders have amassed large quantities of digital clutter, they often find it difficult to delete, even when these files are unused and have little past, present or future relevance.

3. You find files difficult to locate. An obvious consequence of increased quantities of personal digital data is that it becomes harder to organize.

4. You feel emotionally attached to your files. Digital hoarders are more likely to feel an emotional attachment to the files they keep. This is perfectly understandable when referring to a memorable holiday snap, your final college thesis, or a video of your child's first steps. But can we reasonably expect to digitally capture all of life's important moments?

5. You save files across multiple devices and platforms. Another defining trait of a digital hoarder is their tendency to excessively save and share digital files across various devices and platforms. These habits might involve emailing oneself and others to transfer files in an attempt to secure them. These practices lead to the duplication of digital files, creating numerous versions stored across personal devices and cloud storage services.

### **Shopper Hoarding**

If chronic shoppers are also hoarders they will tend to hold on to every item they purchase, even if they have no practical use for it. Sometimes these items can contain volatile chemicals, such as propane, increasing the chance of fire and explosion in the home. Hoarders will hold on to these items even if rooms in their home become unusable because they can't bring themselves to let go of them.

Some common examples of items bought in shopper hoarding situations include:

- Food
- Clothing
- Antiques and Collectibles
- Survival Gear and Equipment
- Items from home shopping television networks
- Common household items such as vacuums or propane tanks

### **Food Hoarding**

When a person returns home with dozens of shopping bags full of groceries with an already full refrigerator and freezer, and cabinets, this person may suffer from food hoarding. Some food hoarders also have difficulty throwing away food that has rotted. This is not only wasteful but the food may attract vermin and insects, posing a large health risk to the hoarder and their family because of potential exposure to viruses and bacteria.

### **Garbage and Trash Hoarding**

When a person displays an inability to discard garbage, waste, or trash, they may be identified as a garbage hoarder. Garbage hoarders rummage through other people's trash to find things to bring back home. This inability to decipher between harmful waste and items of value can be dangerous due to the vermin and insects that the garbage attracts. Vermin and insects may live amongst the trash in the home, wreaking havoc on the home's structure from damage caused by the vermin and or insects. These vermin and or insects also pose a health risk to the homes inhabitants by carrying viruses and diseases. Also, vermin and pests will leave behind their urine and feces while searching for food and living in the home, which adds to the potential health hazards that vermin and pests bring. Should a human be exposed to these health hazards serious illness or even death can occur. Also, garbage hoarders may collect common household items thrown away as trash that contain potentially harmful chemicals such as propane, which may cause a fire and or an explosion in the home if not kept or maintained properly.

**Recycle Hoarding**

The key motivation behind recycle hoarding is a fear of waste. Hoarders often have plans to haul in all of their hoarded items to a recycling factory, so they end up with piles of cardboard, plastic, and more. This can lead to a lot of dust and mold that impair air quality in the home. In cases where the hoarder is keeping empty food packages, there is an even bigger potential for unsanitary conditions to develop.

Not all recycle hoarders plan to use traditional recycle methods. Some of them try to hold onto broken or abused items because they have plans to fix the object and give it to someone who will appreciate it eventually. This can lead to piles of obsolete electronics, broken appliances, or torn clothing.

Unlike hoarders who want to hold onto objects for as long as possible, recyclers want to eventually pass their items on to other people. Unfortunately, when they are actually confronted with the idea of giving away the objects, they may find it fairly difficult. In some cases, recycling hoarders are happy to give items away, but they just accumulate items so quickly that they cannot find willing people to take their objects.

**Paper Hoarding**

Paper hoarders have difficulty discarding paper that they have accumulated. Many people keep papers like bills, invoices, books, news papers, magazines, special offers, and more but paper hoarders keep so many pieces of paper that they make the space that they are kept in unusable. Often the paper is piled up creating stacks of paper that can present danger to the hoarder and their loved ones as a falling hazard, fire hazard, tripping hazard, etc. In severe cases people are trapped beneath a stack of paper that happens to fall, the paper causes a fire, or the paper stacks cause someone to trip, all of which can lead to serious injury or death.

**Sentimental Hoarding**

Sentimental hoarders have a longing for the past. When something takes on meaning in their lives, they refuse to let it go under the pretense they will be letting go of parts of themselves. Clothing hoarding could fall under the sentimental hoarding category.

The reasons someone might hoard things for sentimental reasons include:

- Not wanting to get rid of things that remind them of loved ones
- Holding on to things that remind them of specific places or adventures
- Holding onto things from a certain time period
- Holding onto things that they have been deprived of at some important time in their lives

Many people have a few items they feel emotionally attached to, but a hoarder has an excessive attachment to many possessions and will be uncomfortable if somebody touches them or asks to borrow their items.

**Collector Hoarding**

People who struggle with collector hoarding pick a subject, such as toy cars or snowglobes, and then they try to hold onto as many of these items as possible. Unlike the average collector, hoarders typically keep anything related even slightly to their topic of interest.

**Animal Hoarding**

Animal hoarding is when someone obtains and keeps unhealthy quantities of animals to the point where they cannot provide a safe environment for their animals. In many animal hoarding cases the animals will use the inside of the home as a place to poop and or pee and the messes never get cleaned up. This is a

dangerous environment for not only the animals to live in but for their owners as well, because animal waste can cultivate bacteria, viruses, and parasites that can get both animals and humans sick and may even lead to death. People who hoard animals may simply be trying to share their love for animals by collecting as many as possible but there is a point where the resources for taking care of these animals is exhausted, leading to an unhealthy environment.

People who hoard animals may collect dozens or even hundreds of pets. Animals may be confined inside or outside. Because of the large numbers, these animals often aren't cared for properly. The health and safety of the person and the animals are often at risk because of unsanitary conditions.

The following responsibilities of animal care are typically overlooked in animal hoarding cases:

- Grooming
- Animal waste maintenance
- Feeding
- Pest/Flea/Heartworm Protection
- Proper exercise for the animals

### **Extreme Hoarding**

Extreme hoarding is often the type of hoarding people think of when they consider this disorder. It is the hoarding style frequently shown on reality television shows because it is quite dramatic looking. People who struggle with compulsive hoarding tend to hold onto large quantities of items and may have one or more parts of their home that are inaccessible due to the clutter. However, those who have extreme hoarding take it even farther.

The houses of extreme hoarders tend to be filled with giant piles of hoarded objects that make almost every room useless. People may not have beds to sleep in or kitchens they can use to make food because every surface is stacked with items. Like all hoarders, extreme hoarders often feel embarrassed by the clutter, and since it has taken over their entire home, they are unable to let friends, family members, or repair people into their homes.

Extreme hoarders have the highest risks of being injured due to their hoarding. Large stacks of items may fall on a hoarder, trapping them or severely harming them. The overwhelmingly large piles of objects are often a breeding ground for mold, roaches, and other pests that can cause illnesses in humans.

## **DIFFERENCE BETWEEN HOARDING AND COLLECTING**

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There can be a very fine line between hoarding and collecting. Often, this style of hoarding starts out as a usual collection. However, those who have other mental issues like depression, anxiety issues, dependence disorders, or attachment disorders may gradually move towards hoarding behaviors as a coping method. Hoarding disorder is different from collecting. People who have collections, such as stamps or model cars, carefully search out specific items, organize them and display their collections. Collections can be large, but they aren't usually cluttered. Also, they don't cause the distress and problems functioning that are part of hoarding disorder. People who collect tend to proudly keep their items on display and derive pleasure from their collections, rather than the guilt, shame, or anxiety associated with hoarding. A collector's items usually have an obvious monetary or personal value and while their home may be crowded, it's not disorganized like a hoarder's where items are often difficult to find.

The compulsions and obsessions associated with hoarding tend to make people feel ashamed or embarrassed of their collections. Hoarders tend to accumulate items for the joy of possession instead of

display, so they often get jumbled up together until the hoarder is not even aware of how much they have. People who hoard tend to do so with an intensity that distinguishes them from collectors and messy people. Their need to acquire and retain even worthless items is compulsive and they have a real difficulty getting rid of things. People who are messy or prone to clutter usually still feel comfortable inviting others into their home. Despite the untidiness, their rooms remain accessible and can be used for their original purpose. A hoarder, on the other hand, may use the bathroom, bedroom, or kitchen to store piles of newspapers, boxes, plastic bags, or other worthless items, making it hard to use the toilet, get to bed, or cook.

Dealing with these cases can be quite tricky because the hoarder believes they are just an average collector. Since they do not see anything abnormal about their behavior, they are less willing to seek help. The difference between a collector and a hoarder is that when someone is hoarding, their daily life is negatively impacted.

### **Hoarder vs. Pack Rat – Is There Actually any Difference?**

In the early stages or in less extreme cases, it isn't always easy for family or friends to differentiate hoarding disorder from being messy and disorganized or just having too much stuff. So, at what point does being a "pack rat" cross the line?

One of the most definitive differences between someone with hoarder disorder and someone who is just a pack rat is the reasoning. A pack rat will clutter up their home or apartment with a lot of stuff, but when pressed for a reason, they'll insist they may have a use for it somewhere or at some time.

A hoarder simply absorbs anything and everything without any definitive purpose for the largest percentage of the stuff they acquire. Pack rats insist they keep things because they will need them. A hoarder gets things to satisfy a subconscious need to just have more stuff. If asked, a hoarder may be hard-pressed to explain why they keep many of the things they keep. Many times, pack rats are also obsessive compulsive organizers. All of their stuff must be stored in an orderly manner. Usually, a pack rat will insist that everything must have a set place where it can be found. Either that or it loses much of its luster and purpose.

A hoarder's obsessive tendency to keep acquiring massive collections of useless stuff eventually takes over their lives. Chairs and tables are unusable, and there is often little more than a narrow path cut through their dwelling to pass from one point to another.

Pack rats are often proud of their acquisitions, eager to show visitors the fruits of their success, albeit a bit on the neurotic side. Hoarders are prone to isolating and avoiding visitors.

Both of these problems can create dangerous situations. However, since the pack rat will notoriously strive to organize their stuff, the potential hazards are usually minimal. Hoarders, however, do not exhibit this type of sense of order.

A hoarder's surroundings often present multiple hazards. One is pest infestation, and the other is a fire hazard. There is also the risk of falling because pathways that are normally free and clear are cluttered.

## **REASONS WHY A PERSON HOARDS**

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Risk factors for hoarding include:

- Personality. Many people who have hoarding disorder have a behavior style that includes trouble making decisions and problems with attention, organization and problem-solving.



- Family history. There is a strong association between having a family member who has hoarding disorder and having the disorder yourself.
- Stressful life events. Some people develop hoarding disorder after experiencing a stressful life event that they had difficulty coping with, such as the death of a loved one, divorce or losing possessions in a fire.

Hoarding occurs for three primary reasons:

- An intense personal attachment to objects (or even trash) others see as trivial
- A belief that many items have intrinsic value (such as artwork found objects like driftwood)
- An assumption that potentially useful items should be saved for “a rainy day”

Hoarding behavior can occur at any age, but it’s particularly common and problematic for seniors. Many aging seniors who hoard already have a history of hoarding behavior. The behavior worsens as hoarding behavior becomes a way to hold onto the past or maintain a sense of control.

People hoard for a number of reasons, but it usually stems from having irrational beliefs about objects that make it so distressing to get rid of things. It may be that the person feels that even an every-day or worthless item has great sentimental value, that it will help them to remember an important event or person they may otherwise forget, or they see the use or uniqueness in things that other people would consider junk.

Some hoarders fear running out of things, have a compulsive need to accumulate free items, or find it impossible to pass up a bargain or deal. Others simply view disposing of things as being wasteful.

Hoarding disorder is most commonly diagnosed in older adults with a family history of hoarding. Some studies suggest that hoarding may run in families. This is because many people with hoarding tendencies also have a close relative who hoards. Sometimes, this may be because of modeling. However, there is also evidence of genetic links to hoarding.

### **Family History or Habits**

It's common for those of us who hoard to have family members who share this behavior, such as a parent or sibling. Some studies suggest that certain genes could make you more vulnerable to hoarding. But family links are very complicated. If you grew up around hoarding, you might have learned some of these habits and behaviors. You could also hoard without any other family members who have problems with hoarding. If you live with someone who hoards, this can result in you having more clutter in your home overall. You might find it really difficult to make changes because you disagree with each other on what to keep or throw away. “I call my mum a hoarder because she is, I just had no idea that I'd become one too. I thought of my childhood and the shame I felt that my house wasn't like my friends' houses.”

### **Traumatic Events**

A specific traumatic event(s) such as a divorce, accident, or the death of someone close, or losing possessions in a fire can also trigger hoarding behavior. It may be an extreme expression of the mind attempting to compensate for a perceived loss of control in the individual. It is also suggested that compulsive hoarding is associated with another mental health problem, such as OCD, other anxiety disorders, depression, PTSD, or ADHD. Still other research indicates that a pre-Alzheimer’s personality can contribute to the development of hoarding disorder.

Trauma could include:

- Being abused, bullied or harassed, including experiencing racism
- Breaking up with a partner
- Experiencing physical health problems
- Losing someone close to you
- Feeling extremely lonely or isolated
- Experiencing long periods of stress, or feeling stressed a lot

For some of us, these experiences could make your hoarding worse if you started doing it before a traumatic period. “It was like she built a wall of stuff to keep everyone out. Having experienced several traumatic events in her life: the loss of her baby (while her father was dying), a terrible divorce, her partner having a heart attack and finally the death of her mother. No-one could hurt her if she was protected by all of this stuff.”

### **Aging**

Hoarding usually develops over many years, and it generally gets worse as a person grows older. Elderly people may have even more difficulty getting rid of “stuff” because those items represent memories. Also, for those who experienced difficult financial situations in the past, there may be fear associated with letting go of anything. Some elderly people simply don’t have the energy or mobility to keep up with their possessions. As a result, they let things pile up rather than asking for help.

For those who are fortunate enough to make it to old age, it can come with difficult consequences as well. Loss of social interactions is prevalent, either due to deaths of family & friends, or illness/injury making it more difficult to connect with others or participate in regular activity. This can leave an individual feeling lonely or isolated, for which they try to fill other things to satisfy that void. Sometimes this turns into hoarding and can become such a strong behavior/compulsion that it spirals out of control.

### **Difficult Feelings**

Hoarding can be related to difficult experiences and painful feelings. You may find these hard to express, face or resolve. Some people say hoarding helps them cope with other mental health problems, or distracts them from feeling very anxious, upset or afraid. There can sometimes be a link between hoarding and impulse control. This is when you find it almost impossible to resist certain actions, such as buying items.

### **Perfectionism and Worrying**

If you hoard things, you might feel very worried about making mistakes – also known as perfectionism. You might also find it hard to make decisions, plan ahead or work out how to do tasks. These could be possible reasons why some of us are more vulnerable to hoarding. For example, you might struggle to sort or group your things into types, or to decide what to keep or throw away. The idea of this might seem so difficult or upsetting that it feels easier not to try. “Sometimes I get triggered because I have anxieties about society's expectations of what I should be doing or achieving.”

### **Childhood Experiences**

Some researchers believe hoarding can relate to childhood experiences of losing things, not owning things, or people not caring for you. This might include experiences like:

- Money worries or living in poverty in childhood.
- Having your belongings taken or thrown away by someone.
- Hardship, emotional abuse or neglect. For example, if your basic needs weren't met, or people didn't treat you with warmth or support

These experiences might make you feel more connected to your belongings or make it hard for you to organize them. “My parents were full of stories of their parents' and grandparents' deprivations, it was part of my world view growing up, and I know that chronic disorganization multiplies the impact of every extra item I have.”

### **Other Physical and Mental Health Issues**

Hoarding can be a symptom of other physical and mental health problems. It's important to know if another health problem is behind hoarding, as this can affect the treatment.

Some health problems that might lead to hoarding include:

- Depression
- Anxiety disorders
- Obsessive-compulsive disorder (OCD)
- Attention-deficit/hyperactivity disorder (ADHD)
- Brain injuries
- Dementia
- Schizophrenia
- Personality disorders
- Alcohol or drug addiction
- Prader-Willi syndrome (a genetic condition)

In these cases, treating the physical or mental health problem may stop your hoarding.

### **The Link Between Hoarding Behavior and Alzheimer's Disease**

For some seniors, hoarding behavior has a clinical cause: both pre-Alzheimer's patients and those vulnerable to anxiety sometimes hoard as a defense mechanism against future loss. Hoarding can feel like a small means of control during the early to middle stages of dementia. The Alzheimer's Association has identified a few possible psychological and medical causes for hoarding, as well as rummaging and hiding behaviors:

- Physical changes in the brain leading to confusion, memory loss, and impaired judgment
- Loss of control
- The desire for a sense of security
- Ability to touch familiar objects brings comfort
- Fear of losing items or being robbed
- Boredom, lack of stimulation, and difficulty initiating new activities

### **Prevention**

Because little is understood about what causes hoarding disorder, there's no known way to prevent it. However, as with many mental health conditions, getting treatment at the first sign of a problem may help prevent hoarding from getting worse. This is especially important because by the time clutter becomes a noticeable problem, hoarding likely has been going on for a while.

## **EFFECTS OF HOARDING ON HEALTH AND WELL-BEING**

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Even though hoarding can be a coping mechanism for dealing with anxiety, trauma, or other mental struggles, it doesn't provide real relief. In addition, hoarding behavior often comes with poor decision making, procrastination, and a lack of organization. And because hoarding is isolating, seniors who hoard typically have limited social interactions. They may even push you away or avoid you, damaging your

relationship. People's perceptions of hoarders can negatively impact a hoarder as well. It's easy for others to see hoarders as dirty or lazy, and those judgments can be difficult for them to hear and handle.

A component that often distinguishes pathological hoarding is self-neglect. Self-neglect can appear as a lack of care in personal hygiene and/or appearance, or the lack of care toward an individual's personal space, such as their room or their home. The individual may no longer experience shame and not maintain typical grooming practices, brush their teeth, shower regularly, wear torn, old, or dirty clothes, for example. In addition to the excess clutter, their home or space may have dirty dishes, accumulated trash, or serious disrepair (e.g., mold problems, bug infestations, unresolved plumbing issues, etc.). Sometimes this condition coupled with extreme hoarding is called Diogenes Syndrome and often affects seniors later in life.

### **Recognizing Hoarding Disorder in a Loved One**

Many of us struggle with "pack rat" tendencies or clutter in our homes, especially as we get older. It's also common for people to resist parting with old possessions that carry a sentimental value. However, hoarding disorder goes beyond untidiness and disorganization.

If someone has hoarding disorder:

They overestimate the importance of possessions, perceiving the need to amass things and then experiencing emotional distress when trying to discard them.

Their accumulated clutter can block doors and stairways in their home, make it difficult to access rooms or carry out household repairs, and increase the risk of injury, accident, or fire.

Dust, mold, mildew, and even bug or rodent infestations in the home can have serious health implications. In the case of animal hoarding, those implications stretch to pets not having the necessary space, food, or veterinary care to stay healthy.

Hoarding is a complex mental condition characterized by collecting too many items, an inability to let go of possessions, and trouble with organization. Until recently, 2015, hoarding was considered by mental health professionals as a form of obsessive compulsion (OCD). Now, doctors consider hoarding disorder as its own, unique mental health problem. While hoarding seems to be related to OCD, a vast percentage of individuals with hoarding problems do not exhibit other OCD symptoms. You can experience both obsessive compulsive disorder (OCD) and hoarding disorder at the same time. But experiencing hoarding disorder does not mean you have OCD. They are two different conditions. Even though some experts consider it a subtype of OCD, typical treatment plans have not been shown to be effective at treating the symptoms of hoarding.

Hoarding is more than just a nuisance for family caregivers and other care providers. Clutter takes over living spaces, stripping the functionality from kitchen counters, sinks, bathrooms, and more. This ultimately affects a senior's quality of life. The problem reaches a pathological threshold when the individual is saving things that have no value (junk mail, plastic bags beyond reuse, etc.) and feelings of anxiety and anguish arise at even the thought of throwing away or parting with such items. As mentioned previously, these accumulations of items can prevent ease of movement throughout the home or space, and even become physical or health hazards, yet the individual feels more compelled to hoard than to remedy the situation. Additionally, as individuals are moved into an assisted living situation, there is literally and figuratively little space for hoarding behaviors. Health code is obviously stricter and does not allow for a collection of excess materials to accumulate, as it presents major health & safety code violations, as well as preventing personnel from safely accessing the residents, health supplies, or perform daily or necessary tasks properly.

Getting too many items and refusing to part with them results in:

- Disorganized piles or stacks of items, such as newspapers, clothes, paperwork, books or sentimental items.
- Items that crowd and clutter your walking spaces and living areas. Rooms can't be used for the intended purpose, such as not being able to sleep in your bed.
- Buildup of food or trash to large, unsanitary levels.
- Distress or problems functioning or keeping yourself, others and pets safe in your home.
- Conflict with others who try to reduce or remove clutter from your home.
- Relationship issues, avoiding social activities and employment problems.
- Difficulty organizing items and sometimes losing important items in the clutter.

### **Complications**

Physically, hoarding behavior creates the following problems.

- Difficulty walking safely through a room (risk of falling)
- Increased risk of falls.
- Injury or being trapped by shifting or falling items.
- Family conflicts.
- Refusal of help and increased social isolation
- Unsanitary living conditions
- Fire risk, particularly when items are hoarded in the kitchen
- Inability of emergency responders to reach them in the event of an emergency
- Expired food in the refrigerator or pantry
- Poor nutrition or food poisoning from expired food and beverages
- Poor medication compliance
- Poor work performance.
- Struggle to find things you need. This can sometimes lead to money problems, for example if you can't keep on top of bills and letters.
- Avoid letting people into your space or having difficulty answering the door. This could mean you don't have visitors or get repairs done, which could lead to housing problems.
- Find it hard to keep yourself clean. For example, if you can't access your bathroom or washing machine.
- Find it hard to cook and eat food. This might be because you can't access your kitchen or there's no room inside your fridge.
- Legal issues, such as eviction.
- Other mental health disorders

But the repercussions of hoarding aren't just physical. There are social and emotional ramifications of hoarding behavior.

- Unpaid bills hiding in piles of mail
- Difficulty managing daily living in a cluttered environment
- Frustration and stress from lack of organization
- Loneliness and social isolation
- Shame

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## MISCONCEPTIONS AND STIGMA

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Many of us have heard of hoarding, but this doesn't mean that we all understand it. The word 'hoarding' is sometimes used in the wrong way, such as:

- The media referring to panic buying as hoarding. This can happen during natural disasters or events like the coronavirus pandemic.
- People calling themselves 'hoarders' because they collect items or have more clutter than usual.

The media might also show hoarding in a very extreme way, which is different to many experiences. This can make it difficult to recognize that you're hoarding or tell other people about your experiences. People might also make hurtful assumptions about hoarding, such as thinking it means being unclean or lazy. Hoarding doesn't mean you need help tidying up – it's unhelpful if people try to do this for you. It can feel frustrating and upsetting if people don't understand this, but it's important to remember that you are not alone.

- Hoarding is the same thing as being disorganized

While being disorganized can be a problem itself, it is not as severe as hoarding. The major difference between someone who is hoarding and someone who is messy is hoarding can make it difficult for the person to function. People may accumulate so many items they can no longer sit on the sofa or use the stove. A person who hoards is often unable to get rid of such items even when they are no longer useful or they interfere with daily living. A messy person is usually able to let things go when necessary.

Hoarding is far more serious than being disorganized. Compulsive hoarding can affect a person's ability to maintain relationships, keep a job, and take care of personal and household needs.

- Cleaning will immediately solve the problem

Simply attempting to clean up a cluttered space without addressing the underlying issue typically fails to solve the problem. People may spend hours of time and thousands of dollars to clean out a space only to have the person relapse and start accumulating more stuff in just a few months. Those whose homes are cleaned out without their permission also may experience extreme distress, complicating the issue. To completely stop hoarding, a holistic treatment plan may be more effective.

- Hoarders are lazy, dirty, and unmotivated

Stereotyping people with a hoarding condition as dirty or lazy is an unfair stigma. People who hoard may have cognitive deficits in the brain, impairing their ability to make decisions as well as to keep things organized. Studies have also shown there may be a genetic component to hoarding problems.

Rather than being stigmatized, what people with a hoarding condition really need from others is compassion, empathy, and support. Assuming a person who hoards is also dirty adds to the stigma surrounding a hoarding condition. The term hoarding most often refers to the accumulation of objects and clutter rather than dirt. It is common for a person who hoards to keep a clean house despite the clutter.

Hoarding is also common after a major loss when a person is unable to cope with grief in a healthy way. People who hoard are not lazy; they are just less capable than the average person at carrying out tasks and making decisions. Rather than being stigmatized, what people with a hoarding condition really need from others is compassion, empathy, and support.

- Hoarders are collectors

Hoarding and collecting are two different things. Collectors tend to keep their items organized and proudly on display for others to see. People who hoard will rarely display their possessions, usually

keeping their belongings in complete disarray. They often feel embarrassment and shame when others see their mess.

Hoarding also differs from collecting because it often prevents normal usage of the home. For example, a person's kitchen appliances may no longer be accessible as a result of clutter.

- Hoarders cannot stop hoarding

Though it can be difficult for an affected person to stop hoarding, compulsive hoarding can be treated. Medication has not been shown to be effective against hoarding, though it may help alleviate some of the symptoms associated with it such as depression and anxiety.

Long-term therapy can effectively treat hoarding when combined with adequate education and support. Hoarding generally requires a holistic and comprehensive treatment program that addresses all aspects of a person's life.

- Hoarding can be treated by a single medical professional

Hoarding is a multi-faceted issue and typically requires a team of professionals to effectively treat the problem. Some professionals that may be involved in the treatment process include psychiatrists, therapists, counselors, professional organizers, building inspectors, and landlords, among others. These teams are often referred to as task forces, and approximately 75 cities currently have them in place to help those in the community who are struggling with hoarding.

Public stigma develops from the general population's beliefs in stereotypes about a group, resulting in prejudice and discrimination. For example, the public might mistakenly think all people with obsessive-compulsive disorder are concerned with germs, and this stereotype could cause a cleaning company not to hire a job candidate who has disclosed her obsessive-compulsive disorder.

When an individual suffering from a condition such as obsessive-compulsive disorder or hoarding disorder then internalizes these public views, this is referred to as self-stigma. For example, a person with hoarding disorder may start to accept a stereotype that all people with hoarding are "just lazy." This stereotype then becomes a part of his identity. He may even start to think that he cannot remove clutter or pursue treatment because he's "just lazy."

It is possible that self-stigma, and specifically concerns about prejudice and discrimination, may then cause individuals to avoid places where they may be assigned a label (e.g., avoiding a mental health treatment center to prevent being "labeled" as mentally ill or as someone with a diagnosis of obsessive-compulsive disorder). Thought of in this way, stigma can actually prevent those with obsessive-compulsive disorder or hoarding disorder from seeking treatment.

In addition to public and self-stigma, we were interested in three additional levels of stigma in relation to obsessive-compulsive disorder and hoarding disorder:

- Difference ("They aren't like me")
- Disdain ("They are bad")
- Blame ("They are to blame")

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## SIGNS AND SYMPTOMS

The first symptoms of hoarding disorder often appear during the teenage to early adult years. You may get and save too many items, gradually build up clutter in living spaces, and have difficulty getting rid of

things. As you grow older, you may continue getting and holding onto things that you may never use and don't have space for. By middle age, the clutter can become overwhelming as symptoms become more severe and increasingly difficult to treat. Problems with hoarding gradually develop over time and tend to be a private behavior. Often, major clutter has developed by the time it reaches the attention of others.

Symptoms of hoarding disorder may include:

- Getting and keeping too many items that you may not have a need for right now and don't have space for.
- Ongoing difficulty throwing out or parting with your things, regardless of their actual value.
- Feeling a need to save these items and being upset by the thought of getting rid of them.
- Building up clutter to the point where you can't use rooms.
- Trying to be perfect and avoiding or delaying decisions.
- Problems with planning and organizing

The next time you visit an elderly parent or beloved senior, take a good look around their home for signs of clutter or untidiness.

Are living conditions cramped?

Is it difficult to move from room to room?

Can you find open spaces to sit down or place your purse?

Are countertops, sinks, and tables piled with dirty dishes and other items?

Does the garage or basement appear to be a dumping ground?

Are out-of-date medications and expired food items creating a mess?

Hoarding normally starts in the place you live But you might expand or use other spaces such as a car, garage or storage unit. You may also keep things at other people's homes, if they allow you to.

While hoarding, you might:

- Only realize you are hoarding when other people are in your space.
- Not be able to tell you're hoarding – sometimes called 'clutter blindness'.
- Realize that it's affecting your life but find it hard to stop or know how to change.

Some of us who hoard do not know we are hoarding or cannot see how it impacts our lives. People with hoarding disorder may not see it as a problem, so getting them to take part in treatment can be challenging. Despite their disordered and sometimes unsanitary living conditions, some people with hoarding disorder may not identify their behavior as problematic. Therefore, it can take multiple attempts to begin a conversation about changing their habits.

Whether you're broaching the subject for the first time or have tried and failed to engage your loved one in a conversation about their hoarding before, how you approach the problem can make a big difference. Pushing your loved one to make major changes at once, trying to take charge, or cleaning away their possessions behind their back will only alienate the person, destroy their trust, and add to the family conflict. Rather, it's important to show that you empathize with the hoarder's struggle and want to support and assist them as they work to change their behaviors.

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## STANDARDIZED ASSESSMENTS

### The Structured Interview for Hoarding Disorder

The tool is available at <https://academic.oup.com/edited-volume/34465/chapter/292423918>



The authors hold the copyright, but the scale is free to use by researchers and clinicians who have an interest in hoarding disorder.

The questions contained in this interview relate to each of the six criteria needed to evaluate the presence of hoarding disorder and its two specifiers. These questions appear in bold print and should be asked during the course of the interview, whereas the text in italics is present only to assist the rater. For a diagnosis of hoarding disorder all six criteria must be endorsed

#### Criterion A

Persistent difficulty discarding or parting with possessions, regardless of their actual value.

- Do you experience difficulty discarding or parting with possessions?
- How long have you had this problem?
- What items do you find most difficult to discard?

#### Criterion B

This difficulty is due to a perceived need to save items and to distress associated with discarding them.

- Do you intentionally keep these items? Are they important or useful for you?
- Do you generally feel distressed or upset when discarding possessions?

#### Criterion C

The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromised their intended use. If living areas are uncluttered, it is only because of the interventions of third parties.

- Do you have a large number of possessions that congest and clutter the main rooms in your home?
- Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?
- Have other people, such as family members or local authorities, helped you to remove or forcibly removed some of your possessions? If so, how cluttered was your house or room before their intervention?

#### Criterion 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.

- Do the difficulties discarding or the clutter cause you distress?
- Do the difficulties discarding or the clutter interfere with your family life, friendships, or ability to perform well at home or work?

#### Criterion E

The hoarding is not attributable to another medical condition, for example, brain injury, cerebral vascular disease.

- Do you have any General Medical conditions, a history of head injury or cerebrovascular disease?
- Did you have difficulties with discarding or clutter before you became ill?

#### Criterion F

The hoarding is not better explained by the symptoms of another mental disorder.

### Specifiers

**Excessive Acquisition Specifier.** If the difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space

**Insight Specifier.** Good or fair, poor, absent or delusional

**Risk Assessment.** This section helps the Raider document any possible risks associated with problematic hoarding behavior. They should check whether any of the following are present: fire hazard, blocked exits, risk of falling, insects or infestations, unhygienic conditions, neglect of children elder or disabled people, animal hoarding.

Other Inventories contained in this assessment include:

- Saving Inventory
- Hoarding Severity Scale
- ADL in Hoarding Scale
- Saving Cognitions Inventory
- Compulsive Acquisition Scale
- Home Environment Index

### Hoarding Rating Scale

Available at

<http://www.philadelphiahoarding.org/resources/Hoarding%20Rating%20Scale%20Assessment%20Tool.pdf>

The Hoarding Rating Scale is a brief scale that can be given as a semi-structured clinician interview or as a questionnaire. This tool includes questions about clutter, difficulty discarding, excessive acquisition, and the resulting distress and impairment caused by hoarding. Initial studies suggest that a score of 14 or higher on the HRS indicates a probable hoarding problem/HD diagnosis.

The rater uses the following scale when answering the questions:

**0** = no problem  
**2** = mild problem, occasionally (less than weekly) acquires items not needed, or acquires a few unneeded items  
**4** = moderate, regularly (once or twice weekly) acquires items not needed, or acquires some unneeded items  
**6** = severe, frequently (several times per week) acquires items not needed, or acquires many unneeded items  
**8** = extreme, very often (daily) acquires items not needed, or acquires large numbers of unneeded items

- Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?
- To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?
- To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?
- To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?

- To what extent do you experience impairment in your life (daily routine, job / school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?
- Because of the clutter or number of possessions, how difficult is it for you to use the rooms in your home?
- To what extent do you have difficulty discarding (or recycling, selling, giving away) ordinary things that other people would get rid of?
- To what extent do you currently have a problem with collecting free things or buying more things than you need or can use or can afford?
- To what extent do you experience emotional distress because of clutter, difficulty discarding or problems with buying or acquiring things?
- To what extent do you experience impairment in your life (daily routine, job / school, social activities, family activities, financial difficulties) because of clutter, difficulty discarding, or problems with buying or acquiring things?

Interpretation as follows:

**Interpretation of HRS Total Scores (Tolin et al., 2010)**

Mean for Nonclinical samples: HRS Total = 3.34; standard deviation = 4.97.

Mean for people with hoarding problems: HRS Total = 24.22; standard deviation = 5.67.

Analysis of sensitivity and specificity suggest an HRS Total clinical cutoff score of 14.

**Criteria for Clinically Significant Hoarding: (Tolin et al., 2008)**

A score of 4 or greater on questions 1 and 2, and a score of 4 or greater on either question 4 or question 5.

### **Saving Inventory-Revised (SIR)**

Available at <http://www.philadelphiahoarding.org/resources/Saving%20Inventory%20-%20Revised.pdf>

The Saving Inventory-Revised is a 23-item questionnaire designed to measure three features of HD: excessive acquisition, difficulty discarding, and clutter. Scoring instructions are located at the end of the questionnaire, along with a table showing the average scores of people who do not suffer from HD, as well as cutoff scores that typically indicate a significant clinical hoarding problem and/or HD diagnosis.

Questions are rated using the following scale:

0 = None

1 = A little

2 = A moderate amount

3 = Most/Much

4 = Almost All/Complete

Questions include the following:

**In the past week:**

1. How much of the living area in your home is cluttered with possessions? (Consider the amount of clutter in your kitchen, living room, dining room, hallways, bedrooms, bathrooms, or other rooms).
2. How much control do you have over your urges to acquire possessions?
3. How much of your home does clutter prevent you from using?

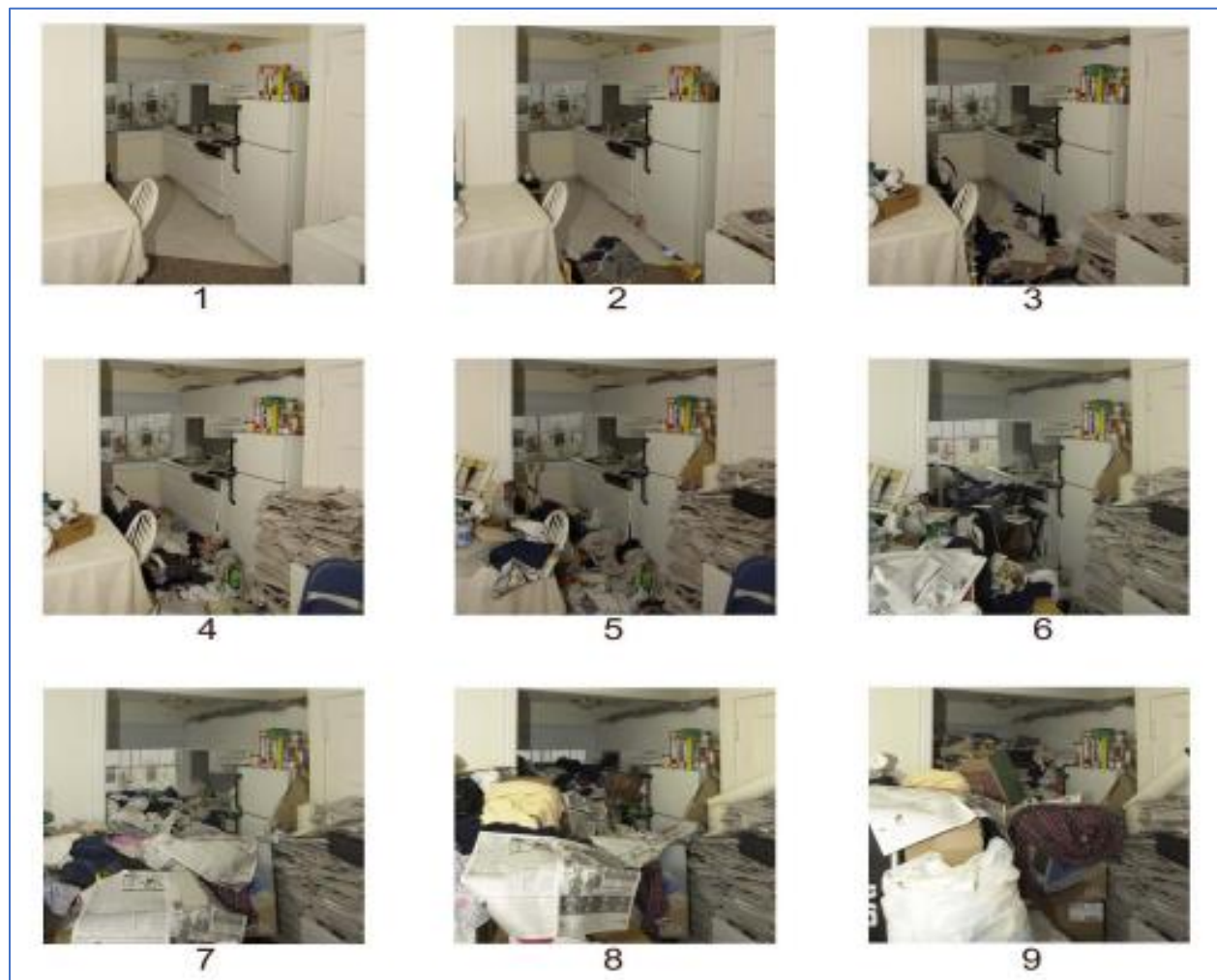
4. How much control do you have over your urges to save possessions?
5. How much of your home is difficult to walk through because of clutter?
6. To what extent do you have difficulty throwing things away?
7. How distressing do you find the task of throwing things away?
8. To what extent do you have so many things that your room(s) are cluttered?
9. How distressed or uncomfortable would you feel if you could not acquire something you wanted?
10. How much does clutter in your home interfere with your social, work or everyday functioning? Think about things that you don't do because of clutter.
11. How strong is your urge to buy or acquire free things for which you have no immediate use?
12. To what extent does clutter in your home cause you distress?
13. How strong is your urge to save something you know you may never use?
14. How upset or distressed do you feel about your acquiring habits?
15. To what extent do you feel unable to control the clutter in your home?
16. To what extent has your saving or compulsive buying resulted in financial difficulties for you?
17. How often do you avoid trying to discard possessions because it is too stressful or time consuming?
18. How often do you feel compelled to acquire something you see? e.g., when shopping or offered free things?
19. How often do you decide to keep things you do not need and have little space for?
20. How frequently does clutter in your home prevent you from inviting people to visit?
21. How often do you actually buy (or acquire for free) things for which you have no immediate use or need?
22. To what extent does the clutter in your home prevent you from using parts of your home for their intended purpose? For example, cooking, using furniture, washing dishes, cleaning, etc.
23. How often are you unable to discard a possession you would like to get rid of?

### **Clutter Image Rating**

Available to <http://www.philadelphiahoarding.org/resources/Clutter%20Image%20Rating%20Scale.pdf>

The Clutter Image Rating is a tool that helps standardize definitions of clutter by showing a series of images depicting rooms in various stages of clutter. This allows the client, the clinician, or another observer to select the image on the scale that best corresponds with the state of the main rooms in the home. The CIR contains three sets of 9 pictures to clarify the level of clutter in the kitchen, the living room, and the bedroom. The living room photos can be used to rate other types of rooms in the home. In general, rooms that are rated as picture #4 or higher indicate a probable hoarding problem/HD diagnosis.

Clutter Image Rating – Kitchen



Clutter Image Rating – Bedroom



1



2



3



4



5



6



7



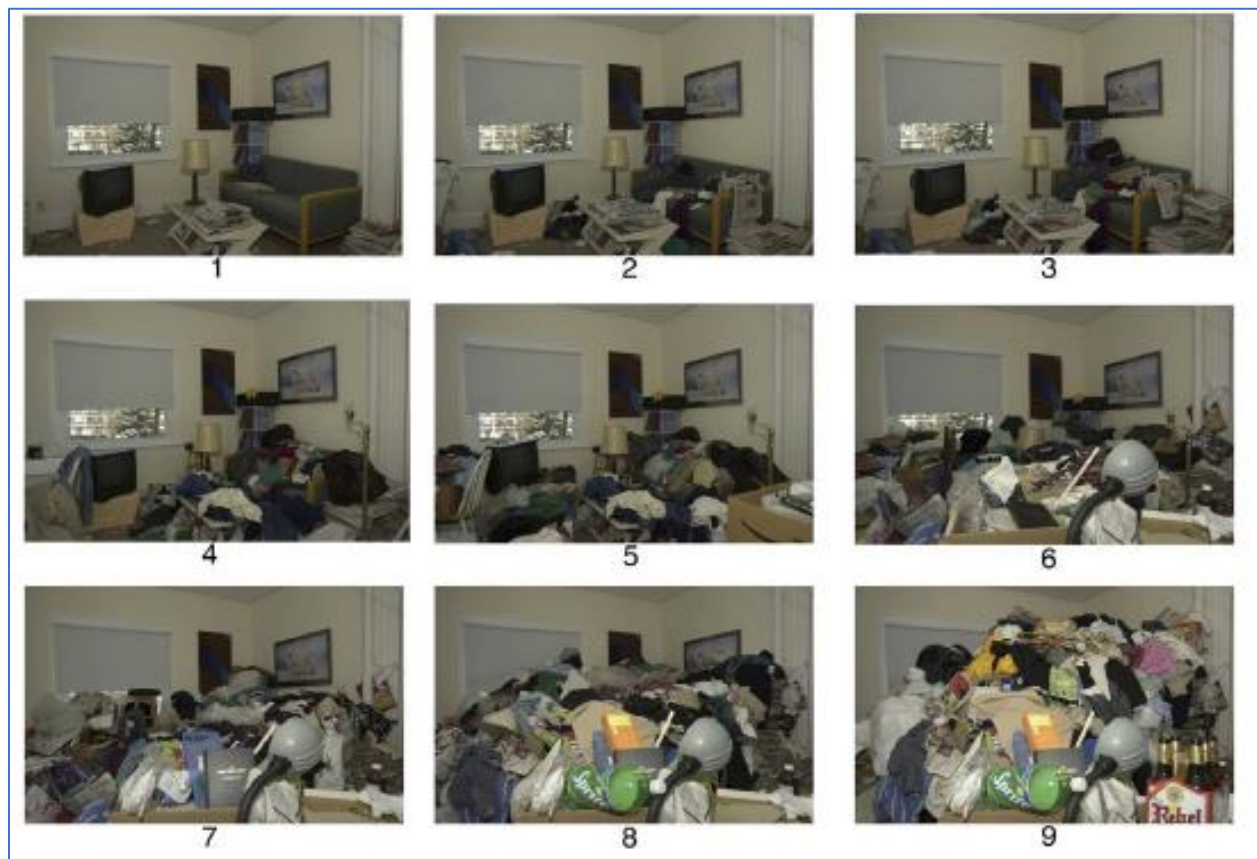
8



9



### Clutter Image Rating – Living Room



## STRATEGIES TO ADDRESS HOARDING

Note: When starting a conversation with a hoarder about their hoarding problem, remember to let the hoarder know that no item will be thrown or given away until the hoarder gives permission. This will go a long way to earning trust which will help complete the cleaning project and set the hoarder up for long-term success! The worst way to deal with another individual's hoarding behavior is to go through their belongings without permission and throw everything away. Even with permission, deep anxiety can arise in the individual just addressing the thought of parting with their item(s), despite any kind of logic or benefit presented.

A study conducted by Boston University School of Social Work revealed that trust is essential in effectively helping an individual with hoarding behaviors. To clarify, trust isn't solely based on the length of time an individual knows someone. Many of us even have family members that we love but may not trust enough or feel entirely comfortable when placed in a vulnerable situation. The same applies to people with hoarding disorders. A strong, genuine rapport must be carefully established; the study indicated that individuals were more receptive to social workers with whom they had developed a trusting relationship.

Obviously, these relationships take time to cultivate and even under the best possible circumstances, mitigating strong hoarding behaviors will continue to be an arduous process. For the short-term, it might seem too time consuming and even frustrating trying to develop this relationship. However, the long-term benefits in investing in this strong foundation will ultimately help in future problems or crises that may arise, and the resident can feel more secure in knowing they have someone they feel is 'safe'.

#### Make the Person a Part of the Process:

- Gently approach the idea of health and safety. Let seniors know you care about their well being.
- Consider control issues. Remind seniors that they need to decide where some of the clutter goes, lest someone else decides for them.
- Draft an agreement. Let seniors help write the agreement about the process so they feel empowered.
- Cheer small victories. If you clear a table completely, celebrate! You can also get creative with the process. Photograph mementos to comfort seniors who are afraid of forgetting. Verbally wish items goodbye. Work slowly and compassionately through the process.

#### Avoid the Power Struggle

One important thing to remember is to keep the individual involved in the process. While an outsider may view them as impeding the process with possible setbacks and a slower timeline in remedying a 'problem space', this will ultimately help resolve the underlying problem instead of hastily applying a band-aid. Part of the hoarding disorder is rooted in control; completely taking the situation away and handling it for them can send the individual into distress and further aggravate their symptoms. By including them in the process, their feelings and concerns are validated, which helps build trust and increases the chances of compliance.

#### Assign a point person

Having one person take the lead when discussing hoarding behaviors can be very useful. Speak with the caregiving team and determine who your loved one is likely to listen to the most.

#### Work together and offer choices

Instead of making all the decisions for an older adult, offer them choices to help them maintain a sense of control. For example, ask if they would prefer to clean the bedroom or kitchen first or if they want a deep cleaning to begin Monday or on the weekend?

#### Control rash reactions and be compassionate

Control your hasty reactions and respond gently when communicating with your senior. Let them know you care about their health, safety, and overall well-being.

#### Address social isolation

A study from the University of California, San Francisco found that 15% of older adults with depression also exhibited extreme hoarding behaviors, versus 2-5% of the older population exhibiting extreme hoarding without the depression comorbidity. Because a snowball effect can exacerbate hoarding behaviors (loneliness or loss of independence leading to depression, depression manifesting into hoarding), providing elderly residents with outlets for social interaction, creativity, movement (exercise, dance, etc.), music, and more can ideally replace hoarding as behaviors used to fill a void. These activities or a combination thereof can really help to inspire confidence, engage the resident, and possibly ease them from their extreme compulsion to hoard.



### Take it slow

Do not rush to clean a senior's home before they are ready unless there is immediate danger, such as visible tripping or fire hazards. Coming into a senior's home and cleaning against their wishes will not fix the problem and may exacerbate it through resentment. It's not unusual to feel overwhelmed if you're trying to cope with a hoarding problem. You might feel like helping yourself will be too hard or take too long. And if you don't know where to start, taking small steps can help you make good progress. For example:

- Set yourself small goals. Try something like throwing away one thing per day.
- Set a timer and try to tidy one area. Or you could limit the time in other ways, like listening to a set number of songs.
- Make a plan. For example, you might schedule one hour a week for cleaning. Try to plan where your items will go, such as in the bin or as a donation. As soon as possible, try to make sure they go exactly where you planned.
- Cancel things like magazine subscriptions or put up a 'no junk mail' sign. This might help to stop new things coming into your home.
- Come up with some rules. Some people use the rule that if they haven't used an item in the last year, they'll get rid of it. Different rules work for different people, but these can help to make decisions easier.
- Explore new activities that don't involve buying or saving things. This could be going for a walk, watching a film or visiting a museum. You could also talk to people close to you about gift giving.
- Try to agree on ways of giving gifts that don't involve physical objects, like having a meal out.

"I started to try to declutter, and it really wasn't easy. I spent days crying, trying to find something that I could part with to get the ball rolling. Eventually I managed to make a start, and it felt great. The more floor I could see the better I felt."

### Staying motivated

You might have been trying to manage your hoarding problem for a while, but sometimes feel like you're getting nowhere. Because of this, you may find it difficult to stay motivated.

Some of these tips might help you keep motivated and notice how far you've come:

- Find ways to track your progress. You could try taking before-and-after pictures of the space you've decided to clean. This can help you see how much progress you've made.
- Make things easier for yourself. This might include using a litter-picking tool to pick things up without touching them, or starting with an area you find easier to clear.
- Find support for related issues. If you're experiencing other issues alongside hoarding, it might help if you look into support for these. This could take some pressure off you. You might be able to find help in our pages on money worries, addiction and housing problems.
- Celebrate your wins. Try going out with friends or watching a TV show you like when you have achieved any goals – no matter how small they may seem.
- Ask for help. You may have someone close to you who could help you. Sometimes just having someone to talk to before or after you clear can feel useful.

### Cleaning Your Senior's Home

After there is a mutual agreement for the need to declutter the home, you may want to use the following strategies:

- Practice safety first
  - Start with the most dangerous areas. Remove any tripping or fire hazards as well as out-of-date medications, expired food, or toxic substances.
- Give them a sense of control

- Offer the choice of what areas to target. It can be helpful to sort possessions into three bins: keep, donate, and throw away. You may want to repeat this process multiple times in the same room.
- Remove items immediately
  - After an item is discarded, make sure to remove it from their residence as soon as possible. Items left in the trash or not removed from the home may be fished out and added back to the clutter.
- Celebrate victories
  - Rejoice each time you clear an area or room. Tell your loved one that progress has occurred and things are getting better.
- Set realistic goals
  - Decluttering a home may take a long time. As long as progress is steady, you are on the right track.
- Get a medical evaluation
  - Have a physician or mental health professional evaluate your loved one as soon as possible. Compulsive hoarding could be caused by a neurological disorder or cognitive decline and may be a sign that medical help is needed.

### **Strategies for Hoarding Behavior with Dementia**

#### **Make rummaging productive**

- Restricting access to all drawers and cabinets can be distressing for a person who enjoys rummaging. Many individuals will rummage or constantly reorganize items because they feel a need to be productive.
- Provide the individual with an opportunity to rummage and make rummaging a stimulating activity. This can be done by providing easy access to some closets, drawers, or portable boxes that contain safe items that the individual can rummage in. They can contain random items or be themed: sewing drawer, sports closet, jewelry box, etc.
- If the individual enjoys sorting and organizing items make this an activity. Ask the person to help you fold and sort items like socks, napkins, and scarves. This may help the person fulfill their desire to be productive.

#### **Protect valuables**

- Put items that cannot be easily replaced in a safe, locked location. These items may include birth certificates, passports, tax records, cash, jewelry, medical records, sentimental photos and letters, etc.
- Get duplicates or “dummies” of items that are commonly misplaced such as glasses, hearing aids, medication, keys, remote controls, cell phones.

#### **Identify and eliminate hiding places**

- Identify the hiding places. Common hiding places include under cushions, under the mattress or bed, under carpets, inside shoes, purses, coat pockets, under stove burners, inside washers and dryers, dishwashers, trash compactors, trash bins, sink drains, and garbage disposals.
- Alarms, battery operated wireless doorbells, and other wireless trackers can be attached to items that are frequently misplaced or hidden and can help to find the item and identify where the person is hiding it. If hiding is a serious problem and hiding places cannot be found, surveillance cameras or “nanny cams” can help identify where an individual is hiding items.
- Check hiding places frequently for lost items. Check the trash before you bring it outside, it is common to find “lost” items in the trash.

- Eliminate some common hiding spots by introducing drain traps, disposal strainers, and drain screens, and disconnecting trash compactors and disposals.
- To discourage hiding and rummaging in certain drawers or closets you may need to install hard-to-open latches or locks on the doors. Placing a STOP sign on the drawer or closet, or camouflaging the door with paint or wallpaper so that it blends in with the room may also discourage a person from using that area for hiding or rummaging.
- Turning a cabinet towards the wall or covering it with a sheet can have an “out of sight, out of mind” effect and eliminate hiding, hoarding, and rummaging in that cabinet.
- Many individuals will hide items or rummage in mailboxes. This can be managed by purchasing a lockable mailbox.

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## DO'S OF COMMUNICATING WITH A HOARDER

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Talking to a hoarder can be a sensitive and difficult topic to broach. Hoarding is often associated with shame, embarrassment, and fear of judgment, which can make it challenging to approach the subject with a loved one who hoards. However, open communication is crucial to helping hoarders overcome their behavior and start the recovery process.

Connect with the individual. Place yourself in the Hoarder's mind and connect with their emotions. They need to know that you will be there for them after the cleanup

Seek professional help. Whether you are a hoarder or a loved one of a hoarder, there are many therapists that specialize in hoarding. Don't just go to a general therapist

Continue to talk about the situation. Follow up on the matter so that the hoarder is motivated to follow through too

Talk about safety. Highlight safety issues first: reorganizing can create a safer home environment, discuss this before discussing the removal of items

Agree that the items are important. Items have an emotional connection to a hoarder so they should be thought of as important to all involved. Baffled? What is something that you have saved in your home that would seem odd to others? Look around your home and you will be surprised

Keep everything confidential. Hoarders realize to some degree that this is not normal to the average society. The goal to keep the hoarder on your side is to promise not to talk about anything related to their situation to anyone without their permission. You can however contact a certified hoarding clean up company that has been trained in hoarding situations

Ask why in a respectful tone. Why are they keeping these items, many hoarders have had a dramatic experience such as a death in the family, a loved one leaving them, or an abusive past which has led to this hoarding situation

Promote donation. Everyone loves to help the needy, so let the hoarder know their stuff will go to better use with someone who needs it, rather than sitting in their house under other items

Be patient and nonjudgmental. Don't get impatient with them, it has to be taken one step at a time. The hoarder needs to realize first that their living condition is below standard. After this is realized, the hardest part of getting rid of certain items has come. It's important to approach the conversation with compassion

and empathy. Avoid criticizing or blaming the hoarder and instead focus on expressing your concern for their wellbeing.

Hire a professional hoarding and cleanup organization service. Hiring a professional service will not only help with the relationship between you and the hoarder but it will allow someone (if hiring the right company) who knows items of value and can help to organize the house in a way that will help the hoarder cope with their feelings and loss of connection with the items

Educate yourself about hoarding disorder first. You may be tempted to view hoarding as a choice or personal failing on the part of the hoarder. But the more you understand about the disorder, the easier it is to be empathetic towards your loved one and offer the most appropriate support.

Listen and use the same language when talking about their possessions. People who hoard aren't any more likely to refer to their possessions as "junk" or "garbage" than the rest of us. Listen to how your loved one refers to their possessions—as "collections" or "things," for example—and follow their lead. It can help you build trust and understanding.

Focus on the safety aspects. Instead of telling your loved one that hoarding is wrong or that no one should live in such mess, focus on the concerns you have for their safety. Emphasizing harm reduction and how you can work together to reduce the risk of accidents or eliminate fire hazards, for example, can often kick-start the process of change.

Offer to help. People who hoard often struggle with decision-making and finding the motivation to change. While it's rarely easy for any of us to accept help from others, your assistance and understanding can be crucial. The key is to offer to work together, at your loved one's pace.

Encourage the hoarder to seek professional help. Even when a hoarder recognizes they have a problem, they can struggle to take the appropriate steps. You can help by offering to research therapists, support groups, and treatment programs in your area. Talk to them about the options available—and offer to accompany your loved one on appointments if that will help to keep them on track.

Use "I" statements. Instead of making accusatory statements, use "I" statements to express how their behavior is affecting you. For example, "I feel overwhelmed and worried about your safety with all the clutter in your home."

Listen actively. Allow the hoarder to express themselves and listen actively to their concerns. This can help build trust and establish a productive dialogue.

Offer support. Let the hoarder know that you are there to support them and that you want to help them overcome their hoarding behavior. Offer to assist with the cleanup process or to accompany them to therapy sessions.

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## **DONT'S OF COMMUNICATING WITH A HOARDER**

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Remember that recovery from hoarding is a process and may take time. It's important to approach the hoarder with patience, empathy, and understanding. By providing support and encouraging them to seek professional help, you can help them on the path to recovery.

Make fun of the hoarder's situation. You would be amazed what comes out of people's mouths. Prepare all who enter a hoarding home that this is a serious mental issue and that the hoarder is feeling very low and embarrassed when you enter the home

Say let's get rid of all this "stuff." To you the mountains of hoarded items may be useless "stuff", but a hoarder has a sentimental emotional connection to the "stuff". For example, they may have saved a menu from a restaurant that is not still in business today, but the menu may be a reminder of a dinner with their late father

Get angry. If you're a loved one of a hoarder your first reaction may be to start getting upset. This emotion will get you nowhere and will actually scare the hoarder, who is very sensitive at the time, and will cause them to close up and not respond to your request to take care of the situation

Try to reason right away. Remember they have been living like this for years and have created a sense of normalcy over time. The first thing you want to say is that you are not judging the person and be as compassionate as possible, this leads to the ability to reason

Touch the hoarder's items. Speaking with the hoarder you can determine what you can clean now and what may need to be negotiated later. Help the hoarder identify items that they have less attachment to and would be ready to get rid of and what they would have trouble getting rid of at first

Treat the hoarder like a child. Hoarders are very intelligent and educated and can tell when you are talking down to them. Any adult would feel disrespected if treated like a child and hoarders are no different so treat them like the adults that they are

Treat hoarders like criminals. There are hoarding situations where the authorities have to get involved. With a reasonable level tone lay out a reasonable timeline that the hoarder must follow before authorities have to intervene and add unnecessary stress and make the hoarder feel like they have broken a major crime

Make a large task list for the hoarder. As a non-hoarder we understand your need to create a plan of attack and begin immediately. Knowing hoarders as we do, we find that separating out the tasks and talking about the tasks individually make the project go smoother

Ask why in a disrespectful tone. It is important to find the answer to this question for the recovery process but ask the question in a respectful tone and let the answer come in due time if they do not know. If you are interested in reading about why people hoard try books by Randy Frost and Gail Steketee.

Let this stress you out. Once the house is organized, with mental health treatment (hoarding is usually a result of a traumatic situation in the hoarders life), a little patience, and periodic check ins, life for the hoarder and their loved ones can become enjoyable again.

Be judgmental. People with hoarding disorder are often socially isolated and feel guilt and shame about their situation. Whether it's in the words you use or your body language, try to listen without negatively judging the person.

Argue with the person. Trying to take control or force the hoarder to act in a certain way will only foster anger and resentment—and even make the hoarder more determined to keep their possessions. The attachment your loved one has for their possessions is real and no amount of arguing will change that.

Try to minimize the challenge. Hoarding disorder doesn't have simple solutions and it takes more than simply clearing away the clutter to address the problem. Just as hoarding developed as a gradual problem, so too recovery will likely be a gradual process, one small step at a time. Recognize that there will likely be setbacks and be prepared for resistance from your loved one when you express your concerns or ideas.

Be discouraging. It's easy to grow frustrated when talking to your loved one and focus only on the negative. But that will just make the hoarder more defensive. Instead, try to be encouraging by acknowledging positive aspects about their home first—the stairs are clear of objects so they won't trip or there's still space on a kitchen counter for them to prepare food, for example. Then you can explore ways of building on that—if the stove was clear of objects as well, that would make it less of a fire hazard to use, or if the pathway from the stairs was a little wider, that would make it safer to move around.

Tell the person what to discard or touch their possessions without consent. The items being hoarded may seem worthless to you, but it's important to allow the hoarder to feel in control. Remain respectful, let your loved one decide what to get rid of, and ask permission before touching anything.

Do not enable your loved one's hoarding. While they may seem like helpful fixes in the short-term, don't offer to store items for the hoarder or pay for extra storage space. In the long run, you'll just make the problem worse. Similarly, don't go shopping or scavenging with the hoarder, gift items that will only add to their hoarding problem, or bail them out of debts incurred by excessive shopping.

Do not clean up after the hoarder. While you'll always want to assist your loved one to clean and organize when they request help, don't take on all the duties yourself. The more you clean up after the hoarder, the less they'll be motivated to address the problem themselves and tackle the real issue—the beliefs and behaviors that fuel their hoarding.

## HELPING THE HOARDER

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If you have a loved one with hoarding disorder, it's easy to feel emotionally overwhelmed. You may be frustrated at your continued failure to get the hoarder to change their behavior, upset at how they live, or stressed by all the conflict it creates in your relationship. You may worry about the financial implications of their excessive shopping, the health problems created by unhygienic living conditions, or the risk of fires and injuries from all the clutter in their home.

If you have to share a living space with the hoarder, things can feel even worse. As the mess continues to mount, you may be angry at the loss of livable area, exasperated by the hoarder's unwillingness to clear out any of their stuff, or offended by how they've claimed certain parts of the home as solely their own. You may even feel that the hoarder cares more about their possessions than they do about you.

While no one should have to live in cramped or unsanitary conditions, it's important to remember that your loved one hasn't chosen to become a hoarder. Hoarding disorder is a complex mental health issue and helping someone goes beyond cleaning out their clutter. Let's look at some guidelines that can help you address the emotional aspects of hoarding as well as the practical challenges. While recovery tends to be gradual, with your support, empathy, and patience, your loved one can regain control over their life.

Examine your own behavior. When you're dealing with someone who hoards, it's easy to lose patience at their behavior, feel stressed at your lack of influence over their living conditions, or even experience burnout from the struggle of trying to help. While you can't control the hoarder's behavior, though, you

can manage your own responses. That starts with taking a step back and exploring how your own actions—or those of other friends or family members—may be contributing to the hoarding problem.

Keep your expectations realistic. Expecting your loved one to become perfectly neat and organized is setting yourself up for disappointment. Changes tend to happen gradually and there will likely be setbacks along the way where the person reverts to old patterns of behavior. Unrealistic expectations can fuel family stress and conflict, so instead of targeting a perfectly neat, clutter-free home, aim at reducing the dangers in your loved one's home. Can you settle for having your loved one live in a cluttered but safe environment, for example?

Manage stress. Dealing with someone who has hoarding disorder can cause a lot of stress, anxiety, and tension—and that can rub off on the hoarder. The more stressed and anxious they become, the more likely they are to revert to negative behaviors. Try to make time to relieve stress and regain your inner calm through exercise, meditation, or other relaxation techniques.

Resolve conflict in a positive way. While conflict is a normal part of every relationship, dealing with a loved one who hoards can trigger strong emotions in anyone. But reacting with angry or hurtful comments, refusing to compromise, or rejecting the things that are important to the hoarder will only push you apart. Instead, you can learn to resolve your differences in healthier ways that can bring you closer together.

Focus on the person, not the possessions. Whether the hoarder is a close friend, partner, or family member, you may forget that the disorder is just one aspect of their identity, not the only thing that defines them as a person. Try to look beyond their accumulation of stuff (or animals) and find other ways of relating. Bonding over other interests or hobbies can help nurture an atmosphere of trust and cooperation.

Don't make everything about hoarding. Spend time talking about other issues and interests. Go for a walk, visit a museum, attend a concert, or take up a new hobby together. People with hoarding disorder are often socially isolated, so your non-judgmental support can be crucial in helping them change their behaviors.

Highlight your loved one's strengths. We all have our strengths and weaknesses. Instead of focusing solely on your loved one's hoarding problem, acknowledge and validate their areas of strength and the things they do well.

Address any underlying conditions. Mental health problems such as depression, anxiety, or OCD may be contributing to your loved one's hoarding. Encouraging them to treat the underlying condition may help improve their hoarding symptoms.

#### Coping with difficult feelings

Trying to manage your hoarding can make you feel emotionally drained. It might bring up lots of difficult feelings, which can make handling practical tasks harder. There are ways you can support yourself and get help for these feelings. For example:

- Talk to someone. You might find it hard to open up about hoarding, but it might help if you share how you're feeling. If you don't feel you can talk to people around you, contact some of the organizations in our useful contacts.
- Try peer support. Connecting with people with similar or shared experiences can be really helpful. For information on where you can find this sort of support, see our pages on useful contacts and peer support.

- Keep a diary. Try noting down your moods and feelings, as well as keeping a note of your hoarding. This could help you spot patterns in what triggers your hoarding behaviors, and the reasons behind difficult feelings.
- Take time to relax. Trying to manage your hoarding can be very hard work – emotionally as well as physically. It can help to find ways to relax that don't involve getting or saving things. For more ideas, see our pages on stress, relaxation and nature.
- Try to take care of yourself. Try to get enough sleep and do enough physical activity to look after your general well-being.

It's a big step to recognize that you might have a hoarding problem and need some help. Even if you're finding it hard, knowing you're working towards change is something to be proud of.

What emotional help do hoarders need?

Not only would a forced cleanup cause extreme emotional distress, the person you care for will immediately return to their hoarding ways and fill up the space again. What works better is to help your older adult see that hoarding is a problem. That doesn't mean shaming the person. Instead, an empathetic and rational discussion (or several discussions) will help them gain the courage to do what's best for themselves.

Start by helping them see that a change needs to be made for their own safety. If the hoarding is linked to a traumatic event, cognitive behavioral therapy (CBT) is often an effective treatment. CBT helps the person cope with the emotions from the trauma and learn to manage their grief in a healthier way. And even if the hoarding isn't linked to a traumatic event, therapy can still be helpful. Hoarding can't truly be fixed until the root of the problem is found and addressed. For some people, medications that treat anxiety and depression may also be able to help with hoarding disorder.

Above all, be empathetic. Try to understand where your older adult is coming from and listen to what they have to say as you gently guide them towards recovery.

By the time hoarding residents reach long-term care, they've generally been engaging in this behavior pattern for decades, so change is unlikely to come easily. Still, with assistance from trained staff members, there is hope for improvement.

- For hoarding residents who have recently left their homes to join the community, provide mental health support immediately — before the clutter has a chance to develop. Residents who have already created a chaotic, unsafe space should also be referred to the consulting psychologist or to the social worker.
- Make referrals for hoarding well in advance of anticipated state surveys. Research shows that it takes months to reduce the clutter.
- Don't purge rooms of belongings without resident consent. Not only is this a violation of the resident's rights, it can lead to extreme emotional distress.
- Use a team approach. While the psychologist or social worker can be the lead, other team members can be trained to assist. Every resident's situation is unique, and it takes a team to address a hoarding problem. Besides the resident and their family, invite input from all disciplines including housekeeping, social services, chaplaincy, the physician, and other specialties. This results in the best plan of care for the resident.
- Give the resident as much control as possible over the process. This can include choosing the area in which to begin, the aides with whom they feel most comfortable working and which items to dispose of first.



- Keep things in perspective. Researchers use tools such as the UCLA Hoarding Severity Scale, which includes photos of cluttered rooms rated 1 through 9 to assess the level of disarray. As can be seen in the pictures, it's very likely that what seems like a terrible mess is actually quite low on the severity scale.

But the State is going to be here any day! What can we do? In that case, you could try the technique used by one clever and pragmatic nursing supervisor — with permission, she boxed up as many of the resident's possessions as possible and stacked the boxes along the wall by the door. Anyone taking a quick look into the room had the impression of a neat and orderly space.

#### How can caregivers help?

While it might be tempting to proactively reorganize and remove clutter from a senior's environment, this is not always beneficial. People with dementia need to feel safe and secure. It is essential to maintain seniors' sense of dignity and control. So, what can you do to help with hoarding behavior?

Take charge of safety first. Even if a senior objects, it is important to remove fire hazards and poisonous materials, such as cleaning fluids, glue, and expired medications. Also move clutter from walkways, heating sources, and stairs. Those items can be piled into a safe place for future organization.

Organize the clutter. Once dangerous items have been removed, sort remaining clutter into large baskets and bins. If living in AL/IL or at home, opt out of catalogs and junk mail.

Make them part of the process. Resist the temptation to swoop in armed with garbage bags and try to clean up the mess as quickly as possible. This is the worst thing we can do. Unfortunately, I often see out-of-town family members do this when they come to visit. While it may seem like a solution to the problem, the results won't last if we don't address the underlying issues. Also, don't secretly throw things away or do a big clean up when the resident is out of their room or apartment. This only causes mistrust and makes them cling even more tightly to their possessions. The resident must be part of the decluttering process. Many people have great success with a three step plan where the caregiver provides three bins: one for items to keep, one for donating, and one for trash. Seniors may need some help going through their clutter but giving them choices will leave them feeling empowered.

Immediately remove all items to be discarded. Once you decide to get rid of items, discard them immediately. Otherwise, aging adults could rummage through the garbage and return items to their homes.

Protect the resident's rights. Hoarding becomes a unique challenge in senior living communities because of residents' rights. A fine line exists between providing care for our residents while not overstepping our boundaries. Some people don't see their hoarding as a problem, so they resist all offers of help. If this is the case, I strongly encourage you to consult your ombudsman. They can help come up with solutions while preserving the resident's rights.

Don't push too hard. In some situations, residents may feel embarrassed by their cluttered space. As a result, they're more willing to accept help with cleaning up the mess. It's still important to allow the resident to maintain a sense of control and not to move too quickly. If you put pressure on the resident, it only increases their anxiety. This could cause the resident to halt the clean-up process and refuse further help.

Access community resources. Over the past several years, our society has become more aware and more understanding of hoarding. As a result, many cities are developing resources to help people overcome this problem. These resources may include educational materials, mental health services, professional organizers, and support groups. Residents of senior living communities can often find help through these resources, too.

Involve mental health specialists. In some situations, a referral to a psychiatrist or psychologist can address underlying mental health problems such as depression or anxiety. Medications may help younger people overcome hoarding tendencies. However, you'll want to be very cautious with psychotropic meds in the elderly because of the high risk of adverse side effects.

Encourage the hoarder to seek treatment and support. Cognitive behavioral therapy (CBT) is the primary treatment for hoarding disorder. Whether in a group or one-on-one setting, CBT can address the negative thoughts that contribute to hoarding disorder and help the hoarder develop new patterns of behavior. Help the person to research therapy options, make and keep appointments, and stay on schedule.

CBT focuses on how thoughts, beliefs and attitudes affect your feelings and behavior. Evidence suggests that both individual and group CBT can help. It also suggests they're more likely to help if you follow a program designed for hoarding disorder – rather than OCD, for example. Hoarding-specific treatments are improving as researchers learn more about what can help.

Together with a therapist, the individual might:

- Examine your beliefs about needing to keep things
- Try to understand why it's hard for you to get rid of things
- Learn skills to help you cope with difficult feelings

Other types of talking therapy may also help you, but experts need more research to find out what could work best.

Working with the right therapist can help the person to:

- Challenge the unhelpful thoughts and beliefs that contribute to their hoarding.
- Resist the urges to acquire more possessions.
- Improve their decision-making and organizational skills.
- Bolster their motivation to declutter.
- Prevent relapse into negative patterns of coping.

#### Offering general support

If you are supporting someone who is hoarding, whether they agree or not, you should try to keep these important points in mind:

- Use respectful language. Don't refer to their possessions as 'junk' or 'rubbish'. This shows that you don't understand their connection to the objects or why they want to keep them. They will be less likely to open up to you if you talk about their things this way.
- Don't focus on a total clean-up. While some people who hoard might be able completely clear their space, this isn't the case for everyone. The important focus should be the safety and wellbeing of your loved one, which can be achieved without completely clearing everything. This is sometimes called a 'harm reduction strategy'. You can find out more on the International OCD Foundation website.
- Listen to what they want. Ask the person close to you what they think will be helpful. This will give them more control over the situation and show you care about what they want. For example, they might want you to sit with them while they clean or for you to help take things to charity shops.

- Think carefully about gifts. It may be unhelpful to give them new items. If you want to give a gift, try thinking of alternatives like going for a meal or day out. Try to be understanding if they get rid of something you've given them. Even if this feels hurtful to you, it might be part of their progress.
- Don't pressure them to let you into their space. They might feel really anxious about visitors, so it's important not to take it personally if they don't invite you in. If you'd like to spend time together, it might help to consider other places you could meet instead.
- Let them know you are there. One of the most important things you can do is let the person you're worried about know that you care. Make sure they know that you can help them find support when they're ready.
- Include your loved one in calls to authorities. You might feel that authorities such as social services, the RSPCA, or the council need to be involved. If so, you should discuss this with your loved one first. This will make them feel more included in the decision and more likely to accept help. You should only call the authorities without their permission if there is a serious risk to safety.

#### Helping to clean or clear

During their process of starting to clean or clear, you can help by thinking about the following:

- Respect their decisions. Most people have some attachment to things they own. You might not understand why they keep particular things. But try to remember that the items they hoard feel important to them – even if they don't seem valuable to you.
- Don't take over their space. It's understandable to want to help them improve things. But if you try to take charge, they might not want to accept any help at all. For example, don't touch or move things without their permission.
- Try to be patient. Once someone seeks help with hoarding, it can still take a long time before they're ready to make changes.
- Help them celebrate successes. Try celebrating after they clear a small area. They might feel very anxious about what's left to do, so it could help if you encourage them to notice achievements. You could also remind them to take things one step at a time.

“Discarding is never a simple yes-no process, and most items will be pondered over through several sort-throughs, over a period of months and years.”

Not everyone is ready to admit that they have problems with hoarding. If someone close to you is in this position, try to:

- Be gentle – you can't force someone to change their behavior. Don't try to persuade, trick or force someone into clearing up or throwing things away. This is unlikely to help them change in the long term and could make them withdraw from you.
- Help them to seek treatment and support. For example, you could encourage them to use the Clutter Image Rating or hoarding ice breaker tools to help them talk to their doctor. For more information, see our pages on helping someone else to seek help. We also have advice on what to do if someone doesn't want help.
- Help them stay safe. Focus on things such as fire safety and emergency access. This can at least make the hoarding situation a safer environment. The London Fire Brigade has tips on its website about how to reduce the risk of fire from hoarding.
- Avoid making threats. Threatening to cut off contact or call authorities like the council is unlikely to help the situation. It can make your loved one feel more alone and less likely to talk to you about what they're going through.

“I feel that my mum is at risk in the event of a fire or if she has a medical emergency. The simple daily tasks that we all take for granted (getting into bed, cooking a meal, going up the stairs) are all made more difficult (and dangerous) by the amount of stuff in her home, and her attachment to it.”

### Family sensitivity towards a hoarder

Hoarding is a sensitive topic for many individuals and is too often not brought up when it needs to be addressed. Sometimes the hoarding situation becomes so severe that family members and loved ones are forced to address the problem. When addressing a hoarding situation, it may be necessary to seek professional help through therapy (a therapist specializing in hoarding disorder) and a hoarding cleanup company that can help put the hoarder on a path towards recovery. When researching licensed therapists, it is important to make sure that they specialize in treating hoarding disorder.

Many times, individuals who are hoarding may be self-conscious of the situation and do not want their family to interfere with their lives or see their living conditions. This isolation can create more problems. Sensitivity and caring language are important considerations to bring into a conversation when addressing a hoarder about their hoarding issue. Exercise patience and avoid negative comments about the individual or their things.

Help motivate your loved one. One of the toughest aspects of helping someone with hoarding disorder is motivating them to start and stick with the process of changing how they accumulate items. The prospect of discarding existing possessions and resisting the urge to purchase more can be emotionally harrowing for the hoarder. Motivating them can take patience, understanding, and lots of encouragement.

Make harm reduction the focus. When setting goals with your loved one about organizing their living space, emphasize reducing the risk of accidents and injuries rather than eliminating clutter. To keep the hoarder motivated, make it clear that the aim is only to get rid of enough items to keep the person safe. As you move ahead with the process, your loved one may become more comfortable making decisions about things to discard.

Set achievable goals. When decluttering, aim to tackle just a small pile or a single drawer at first. Start with items that your loved one finds easiest to throw away—old bills may be less distressing to discard than letters or photographs, for example. Getting rid of just one or two items can be emotionally exhausting for someone with hoarding disorder, so by keeping goals manageable, you'll allow the person to develop a tolerance to the decluttering process and gradually build momentum.

Don't make decisions for them. When helping your loved one organize their things, encourage them to assign possessions to "keep" or "discard" piles rather than any kind of "decide later" category. While you want to avoid them delaying decisions, the final say should always be theirs.

Identify your loved one's shopping habits. What triggers the person to acquire more things? Perhaps they're unable to pass up a bargain or they shop when they're bored, lonely, or stressed. Once you identify what triggers them to accumulate more possessions, you can find healthier ways to deal with the urges.

Celebrate even small victories. Clearing away just a few things is reason to praise your loved one—and yourself. Don't underestimate the importance of small steps and how your efforts are making a difference.

Respect each other's boundaries. Work together to keep these boundaries where you need them. For example, this could involve agreeing that certain spaces need to be clutter-free for safety reasons. Or having a space in the home that's just for you.

Address the hoarding problem together. Work out what common goals you have for your shared space and discuss how you can achieve these together.

Give them space. It might help to give them time alone to sort things out. Some people find it easier to do this without someone else there. For example, you could go see a movie while they clean.

Know your limits. It's OK if you feel you can no longer live in a space where someone is hoarding. It's not always possible to find somewhere else to stay, so it might help to try things like making sure you spend time outside the house regularly. This could include going for walks, visiting friends or going on a day out.

Talking therapy. You can go to some types of talking therapies with the person who is hoarding. This can help you both express how you are feeling. The charity Relate has more information on relationship and family therapy.

#### How can I get my parent to clean up?

For a senior to combat this diagnosis, they need to first be willing to accept the help. Once they have agreed to receiving help, follow the steps below and remember to never rush a hoarder during this process.

- Enlist a cleaning crew -- Family, professionals, etc. and start the process. Find a JUNK collecting organization.
- Set a date to start -- Procrastination is the enemy. A date must be set, and you must follow through with your selected date(s).
- Select one room and work room by room -- Set a time, 3 hours, 4 hours, etc., and stick to that time for each room. If it takes more than one day to complete a room, finish the room before starting on the next room. This is important - you'll need to finish one project before starting the next. This process will help the hoarder see their progress and help them to continue.
- Find a restoration company depending on how bad the situation in the home is. Also find a professional cleaning company to clean the home once the decluttering process has ended.
- Donation -- During the process, think about donating items in good condition. Items with rodent droppings or urine and in bad condition should be discarded.
- New home -- It would be best to reach out to a family friend, Senior Living Consultant, or Care Management group to find placement for your loved one if the home cannot be salvaged. Unless the authorities are already involved and looking for a place for your loved one, it is best to remove them from the home and get them counseling for their hoarding behaviors and any associated disorders.

#### When to see a doctor

Contact a healthcare provider or mental health professional if hoarding makes a living situation unhealthy or unsafe for you or someone you know. If you or a loved one has symptoms of hoarding disorder, talk with a health care provider or a mental health provider with expertise in diagnosing and treating hoarding disorder as soon as possible. Some communities have agencies that help with hoarding problems. Check with the local or county government for resources in your area. If someone you know is hoarding animals, it is important to contact the correct authorities, such as Animal Control Services, to safely acquire and care for the animals.

To diagnose hoarding disorder, your healthcare provider will ask about your collecting and saving habits. To confirm a diagnosis, the following symptoms must be present:

- Ongoing difficulty getting rid of possessions whether they have value or not.
- Feeling a strong need to save items and feelings of distress associated with discarding items.
- Living spaces that are so filled with possessions that they're unusable and/or unsafe.

As hard as it might be, if your loved one's hoarding disorder threatens health or safety, you may need to contact local authorities, such as police, fire, public health, child or elder protective services, or animal welfare agencies.

## CONCLUSION

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Hoarding is characterized by excessive clutter and difficulty discarding. While many individuals may report dissatisfaction and difficulties with such symptoms alongside excessive acquisition, only when these lead to clinically significant distress and/or impairment in social, occupational, or other important areas of functioning is the diagnosis of hoarding disorder considered. Hoarding is associated with significant physical, psychological, and social morbidity leading to reduced quality of life. Even safety can be affected by possessions that congest and clutter active living areas and substantially compromise their intended use.

It's easy to feel frustrated and perhaps even disgusted when dealing with a hoarder. However, we need to remember that this represents a condition that's often beyond a resident's control. Through education, patience, teamwork, and understanding, we can help restore the best quality of life for the resident.

## RESOURCES

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International OCD Foundation provides information for families, mental health professionals, and community responders and maintains a resource directory to locate therapists, treatment programs, clinics, and support groups. <https://hoarding.iocdf.org/>

Hoarding Cleanup (800) 462-7337, provides a nationwide directory of (fee-for-service) hoarding cleanup services and mental health providers specializing in hoarding behavior. Visit their website for information about webinars, and other resources.

For those looking to get organized, the National Association of Productivity & Organizing Professionals offers a "Find a Professional" directory for (fee-for-service) organizers who specialize in serving those with hoarding disorder.

# U.S.A HOARDING RESOURCES



Hoarding is classified in DSM 5 (Diagnostic and Statistical Manual of Mental Disorders) as a separate from OCD. Compulsive hoarding affects approximately 700,000 to 1.4 million people in the US

## UNDERSTANDING HOARDING

### Signs of Hoarding

- Buildup of clutter that blocks either pathways, furniture, or entire rooms
- Overwhelmed or loss of energy feeling upon seeing or entering a room with clutter
- Not letting anyone inside including repairmen and avoiding inviting anyone over
- A need to take free items (condiment & sugar packets, flyers) regardless of need
- Losing important items in the clutter like bills, legal documents, and favorite items
- A purchasing items without an immediate need or stocking up unnecessarily
- Replacing a new appliance and putting it next to the broken one



## HOARDING THERAPISTS

ABCT - Association for Behavioral and Cognitive Therapies

- <http://www.findcbt.org/FAT/index.cfm>

ADAA - Anxiety and Depression Association of America

- <https://members.adaa.org/search/custom.asp?id=4685>

IOCDF - International OCD Foundation

- <https://iocdf.org/find-help/>



## COMMUNITY RESOURCES

- <https://www.nami.org/findsupport>
- <https://www.nlm.nih.gov/health/find-help>
- <https://hoarding.iocdf.org/>
- <https://www.psychologytoday.com/us/therapists/hoarding>
- <https://www.apa.org/>
- <https://members.adaa.org/page/FATMain>
- <https://adaa.org/find-help/support/support-groups>



## ONLINE RESOURCES

- <https://www.reddit.com/r/hoarding>
- <https://www.reddit.com/r/ChildofHoarder/>
- [https://hoardingcleanup.com/chat\\_room](https://hoardingcleanup.com/chat_room)
- [https://hoardingcleanup.com/message\\_board](https://hoardingcleanup.com/message_board)
- [http://childrenofhoarders.com/wordpress/?page\\_id=4092](http://childrenofhoarders.com/wordpress/?page_id=4092)
- <https://www.spca.org/>



## HOARDING FACTS

- Hoarding is linked to a traumatic event, childhood abuse, or neglect.
- There are different types of hoarding.
- Hoarding runs in the family.
- Hoarding can affect the mind causing stress, anxiety, and loss of energy.



## HOARDING CLEANUP



Address Our Mess

**855-676-7848**

**[www.addressourmess.com](http://www.addressourmess.com)**

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## DISCLOSURE

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## HOW TO RECEIVE COURSE CREDIT

Read the entire course online or in print which requires 1.5 (NAB) or 2.0 (Nurse) hour commitment of time. Complete a post-test assessment. You must score 80% or better on the test and complete the course evaluation to earn a certificate of completion for this CE activity. If required, Select Rehabilitation will report attendance to CE Broker.

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## ABOUT THE COURSE AUTHOR

Dr. Kathleen Weissberg, (MS in OT, 1993; Doctoral 2014) in her 30 years of practice, has worked in rehabilitation and long-term care as an executive, researcher and educator. She has established numerous programs in nursing facilities; authored peer-reviewed publications on topics such as low vision, dementia quality care, and wellness; has spoken at numerous conferences both nationally and internationally, for 20+ State Health Care Associations, and for 25+ state LeadingAge affiliates. She provides continuing education support to over 30,000 therapists, nurses, and administrators nationwide as National Director of Education for Select Rehabilitation. She is a Certified Dementia Care Practitioner, Certified Montessori

Dementia Care Practitioner, Certified Fall Prevention Specialist, and a Certified Geriatric Care Practitioner. She serves as the Region 1 Director for the American Occupational Therapy Association Political Action Committee and is an adjunct professor at Gannon University in Erie, PA.

## POST-TEST

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1. Consequences of hoarding can include all but which of the following:
  - a) Fire hazards
  - b) Improved relationships with family and others
  - c) Increased risk of falls
  - d) Health risks
2. TRUE or FALSE: Hoarding is defined as “persistent difficulty discarding or parting with possessions, regardless of their actual value.”
3. Which of the following is not considered a risk factor for hoarding?
  - a) Gender
  - b) Personality
  - c) Family history
  - d) Stressful life event
4. Strategies to address hoarding may include which of the following?
  - a) Take it slow. Set small goals or consider setting a timer and try to tidy one area.
  - b) Stay motivated by tracking progress and celebrating wins
  - c) Avoid the power struggle by keeping the individual involved in the process
  - d) All of the above
5. TRUE or FALSE: People with hoarding disorder may not see it as a problem, so getting them to take part in treatment can be challenging.
6. Which of the following is NOT a way to address hoarding with dementia?
  - a) Make rummaging a stimulating activity
  - b) Restrict access to all drawers and cabinets
  - c) If the individual enjoys sorting and organizing items make this an activity
  - d) Offer items from their past (e.g., yearbook, family photo album)
7. Which of the following statements is true regarding hoarding and collecting?
  - a) Hoarders often do not begin as collectors
  - b) Collecting can be used as a coping method
  - c) Hoarders often experience shame or guilt
  - d) Collections are generally cluttered and cause distress
8. Which of the following statements is true?
  - a) Cleaning will immediately solve the problem
  - b) Hoarders can't stop hoarding
  - c) Hoarding can be treated by a single medical professional
  - d) None of the above, they are all false

9. Which of the following is NOT a “do” when interacting with someone who hoards?
- a) Make a large task list for the hoarder
  - b) Offer support and help
  - c) Focus on safety
  - d) Ask “why” in a respectful tone
10. Types of hoarding may include which of the following:
- a) Digital
  - b) Animal
  - c) Garbage/recycling-
  - d) All of the above

The post-test and corresponding course evaluation can be accessed at:

[https://www.surveymonkey.com/r/When\\_a\\_Resident\\_Hoards\\_-\\_Take\\_Home\\_Course](https://www.surveymonkey.com/r/When_a_Resident_Hoards_-_Take_Home_Course)

Or by using the following QR Code:



If all course requirements have been met, a certificate will be emailed from Select Rehabilitation to the email address reported in the course follow-up survey.

Any questions or issues related to this course should be directed to Dr. Kathleen Weissberg, National Director of Education for Select Rehabilitation at [kweissberg@selectrehab.com](mailto:kweissberg@selectrehab.com)