

# Understanding Hoarding Disorder

*Definition from DSM-5<sup>®</sup>—Understanding Mental Disorders*

## **What is DSM-5<sup>®</sup>—Understanding Mental Disorders**

*Most of us know someone who suffers from a mental illness or we may know we are experiencing this ourselves. The DSM-5<sup>®</sup>—Understanding Mental Disorders book helps those who may be struggling with mental health problems, as well as those who want to help others achieve mental health and well-being. Based on the latest, fifth edition of the Diagnostic and Statistical Manual of Mental Disorders—known as DSM-5<sup>®</sup>—Understanding Mental Disorders provides valuable insight on what to expect from an illness and its treatment—and will help readers recognize symptoms, know when to seek help, and get the right care.*

DSM-5<sup>®</sup>—Understanding Mental Disorders is used globally within the medical profession as a reference to mental health associated circumstances.

## **Diagnostic Criteria**

1. Persistent difficulty discarding or parting with possessions, regardless of their actual value.
2. This difficulty is due to a perceived need to save the items and to distress associated with discarding them.
3. The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use. If living areas are uncluttered, it is only because of the interventions of third parties (e.g., family members, cleaners, authorities).
4. 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).
5. The hoarding is not attributable to another medical condition (e.g., brain injury, cerebrovascular disease, Prader-Willi syndrome).
6. The hoarding is not better explained by the symptoms of another mental disorder (e.g., obsessions in obsessive-compulsive disorder, decreased energy in major depressive disorder, delusions in schizophrenia or another psychotic disorder, cognitive deficits in major neurocognitive disorder, restricted interests in autism spectrum disorder).

Specify if:

- **With excessive acquisition:** If difficulty discarding possessions is accompanied by excessive acquisition of items that are not needed or for which there is no available space.

Specify if:

- **With good or fair insight:** The individual recognizes that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are problematic.
- **With poor insight:** The individual is mostly convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.
- **With absent insight/delusional beliefs:** The individual is completely convinced that hoarding-related beliefs and behaviors (pertaining to difficulty discarding items, clutter, or excessive acquisition) are not problematic despite evidence to the contrary.

## *Specifiers*

### *With excessive acquisition*

Approximately 80%–90% of individuals with hoarding disorder display excessive acquisition ([Frost et al. 2009](#)). The most frequent form of acquisition is excessive buying, followed by acquisition of free items (e.g., leaflets, items discarded by others) ([Frost et al. 2009](#)). Stealing is less common ([Frost et al. 2011b](#)). Some individuals may deny excessive acquisition when first assessed, yet it may appear later during the course of treatment. Individuals with hoarding disorder typically experience distress if they are unable to or are prevented from acquiring items.

## **Diagnostic Features**

The essential feature of hoarding disorder is persistent difficulties discarding or parting with possessions, regardless of their actual value (Criterion A). The term persistent indicates a long-standing difficulty rather than more transient life circumstances that may lead to excessive clutter, such as inheriting property. The difficulty in discarding possessions noted in Criterion A refers to any form of discarding, including throwing away, selling, giving away, or recycling. The main reasons given for these difficulties are the perceived utility or aesthetic value of the items or strong sentimental attachment to the possessions. Some individuals feel responsible for the fate of their possessions and often go to great lengths to avoid being wasteful. Fears of losing important information are also common. The most commonly saved items are newspapers, magazines, old clothing, bags, books, mail, and paperwork, but virtually any item can be saved ([Pertusa et al. 2008](#)). The nature of items is not limited to possessions that most other people would define as useless or of limited value. Many individuals collect and save large numbers of valuable things as well, which are often found in piles mixed with other less valuable items ([Frost and Hartl 1996](#)).

Individuals with hoarding disorder purposefully save possessions and experience distress when facing the prospect of discarding them (Criterion B). This criterion emphasizes that the saving of possessions is intentional, which discriminates hoarding disorder from other forms of psychopathology that are characterized by the passive accumulation of items or the absence of distress when possessions are removed.

Individuals accumulate large numbers of items that fill up and clutter active living areas to the extent that their intended use is no longer possible (Criterion C). For example, the individual may not be able to cook in the kitchen, sleep in his or her bed, or sit in a chair. If the space can be used, it is only with great difficulty. Clutter is defined as a large group of usually unrelated or marginally related objects piled together in a disorganized fashion in spaces designed for other purposes (e.g., tabletops, floor, hallway) ([Steketee and Frost 2003](#)). Criterion C emphasizes the “active” living areas of the home, rather than more peripheral areas, such as garages, attics, or basements, that are sometimes cluttered in homes of individuals without hoarding disorder. However, individuals with hoarding disorder often have possessions that spill beyond the active living areas and can occupy and impair the use of other spaces, such as vehicles, yards, the workplace, and friends’ and relatives’ houses. In some cases, living areas may be uncluttered because of the intervention of third parties (e.g., family members, cleaners, local authorities). Individuals who have been forced to clear their homes still have a symptom picture that meets criteria for hoarding disorder because the lack of clutter is due to a third-party intervention. Hoarding disorder contrasts with normative collecting behavior, which is organized and systematic, even if in some cases the actual amount of possessions may be similar to the amount accumulated by an individual with hoarding disorder ([Nordsletten and Mataix-Cols 2012](#)). Normative collecting does not produce the clutter, distress, or impairment typical of hoarding disorder.

Symptoms (i.e., difficulties discarding and/or clutter) must cause clinically significant distress or impairment in social, occupational, or other important areas of functioning, including maintaining a safe environment for self and others (Criterion D). In some cases, particularly when there is poor insight, the individual may not report distress, and the impairment may be apparent only to those around the individual. However, any attempts to discard or clear the possessions by third parties result in high levels of distress.

### **Associated Features Supporting Diagnosis**

Other common features of hoarding disorder include indecisiveness, perfectionism, avoidance, procrastination, difficulty planning and organizing tasks, and distractibility ([Frost and Hartl 1996](#); [Frost et al. 2011b](#); [Steketee and Frost 2003](#)). Some individuals with hoarding disorder live in unsanitary conditions that may be a logical consequence of severely cluttered spaces and/or that are related to planning and organizing difficulties ([Snowdon et al. 2012](#)). Animal hoarding can be defined as the accumulation of a large number of animals and a failure to provide minimal standards of nutrition, sanitation, and veterinary care and to act on the deteriorating condition of the animals (including disease, starvation, or death) and the environment (e.g., severe overcrowding, extremely unsanitary conditions) ([Frost et al. 2011a](#)). Animal hoarding may be a special manifestation of hoarding disorder. Most individuals who hoard animals also hoard inanimate objects ([Frost et al. 2011a](#)). The most prominent differences between animal and object hoarding are the extent of unsanitary conditions and the poorer insight in animal hoarding.

## Prevalence

Nationally representative prevalence studies of hoarding disorder are not available. Community surveys estimate the point prevalence of clinically significant hoarding in the United States and Europe to be approximately 2%–6% ([Pertusa et al. 2010](#)). Hoarding disorder affects both males and females, but some epidemiological studies have reported a significantly greater prevalence among males. This contrasts with clinical samples, which are predominantly female. Hoarding symptoms appear to be almost three times more prevalent in older adults (ages 55–94 years) compared with younger adults (ages 34–44 years) ([Pertusa et al. 2010](#)).

## Development and Course

Hoarding appears to begin early in life and spans well into the late stages. Hoarding symptoms may first emerge around ages 11–15 years, start interfering with the individual's everyday functioning by the mid-20s, and cause clinically significant impairment by the mid-30s ([Grisham et al. 2006](#); [Landau et al. 2011](#); [Tolin et al. 2010b](#)). Participants in clinical research studies are usually in their 50s ([Frost et al. 2011b](#); [Pertusa et al. 2008](#)). Thus, the severity of hoarding increases with each decade of life ([Landau et al. 2011](#)). Once symptoms begin, the course of hoarding is often chronic, with few individuals reporting a waxing and waning course ([Tolin et al. 2010b](#)).

Pathological hoarding in children appears to be easily distinguished from developmentally adaptive saving and collecting behaviors ([Plimpton et al. 2009](#)). Because children and adolescents typically do not control their living environment and discarding behaviors, the possible intervention of third parties (e.g., parents keeping the spaces usable and thus reducing interference) should be considered when making the diagnosis.

## Risk and Prognostic Factors

### *Temperamental*

Indecisiveness is a prominent feature of individuals with hoarding disorder and their first-degree relatives ([Samuels et al. 2007](#)).

### *Environmental*

Individuals with hoarding disorder often retrospectively report stressful and traumatic life events preceding the onset of the disorder or causing an exacerbation ([Grisham et al. 2006](#); [Landau et al. 2011](#)).

### *Genetic and physiological*

Hoarding behavior is familial, with about 50% of individuals who hoard reporting having a relative who also hoards ([Pertusa et al. 2010](#)). Twin studies indicate that approximately 50% of the variability in hoarding behavior is attributable to additive genetic factors ([Iervolino et al. 2009](#)).

## Culture-Related Diagnostic Issues

While most of the research has been done in Western, industrialized countries and urban communities, the available data from non-Western and developing countries suggest that hoarding is a universal phenomenon with consistent clinical features ([Mataix-Cols et al. 2010](#)).

## Gender-Related Diagnostic Issues

The key features of hoarding disorder (i.e., difficulties discarding, excessive amount of clutter) are generally comparable in males and females, but females tend to display more excessive acquisition, particularly excessive buying, than do males ([Frost et al. 2011b](#)).

## Functional Consequences of Hoarding Disorder

Clutter impairs basic activities, such as moving through the house, cooking, cleaning, personal hygiene, and even sleeping. Appliances may be broken, and utilities such as water and electricity may be disconnected, as access for repair work may be difficult. Quality of life is often considerably impaired ([Saxena et al. 2011](#)). In severe cases, hoarding can put individuals at risk for fire, falling (especially elderly individuals), poor sanitation, and other health risks. Hoarding disorder is associated with occupational impairment, poor physical health, and high social service utilization. Family relationships are frequently under great strain. Conflict with neighbors and local authorities is common, and a substantial proportion of individuals with severe hoarding disorder have been involved in legal eviction proceedings, and some have a history of eviction.

## Differential Diagnosis

### *Other medical conditions*

Hoarding disorder is not diagnosed if the symptoms are judged to be a direct consequence of another medical condition (Criterion E), such as traumatic brain injury, surgical resection for treatment of a tumor or seizure control, cerebrovascular disease, infections of the central nervous system (e.g., herpes simplex encephalitis), or neurogenetic conditions such as Prader-Willi syndrome ([Mataix-Cols et al. 2010](#)). Damage to the anterior ventromedial prefrontal and cingulate cortices has been particularly associated with the excessive accumulation of objects ([Anderson et al. 2005](#); [Mataix-Cols et al. 2011](#)). In these individuals, the hoarding behavior is not present prior to the onset of the brain damage and appears shortly after the brain damage occurs ([Anderson et al. 2005](#)). Some of these individuals appear to have little interest in the accumulated items and are able to discard them easily or do not care if others discard them, whereas others appear to be very reluctant to discard anything ([Mataix-Cols et al. 2011](#)).

### ***Neurodevelopmental disorders***

Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of a neurodevelopmental disorder, such as autism spectrum disorder or intellectual disability (intellectual developmental disorder).

### ***Schizophrenia spectrum and other psychotic disorders***

Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of delusions or negative symptoms in schizophrenia spectrum and other psychotic disorders ([Mataix-Cols et al. 2010](#); [Pertusa et al. 2010](#)).

### ***Major depressive episode***

Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of psychomotor retardation, fatigue, or loss of energy during a major depressive episode.

### ***Obsessive-compulsive disorder***

Hoarding disorder is not diagnosed if the symptoms are judged to be a direct consequence of typical obsessions or compulsions, such as fears of contamination, harm, or feelings of incompleteness in obsessive-compulsive disorder (OCD). Feelings of incompleteness (e.g., losing one's identity, or having to document and preserve all life experiences) are the most frequent OCD symptoms associated with this form of hoarding. The accumulation of objects can also be the result of persistently avoiding onerous rituals (e.g., not discarding objects in order to avoid endless washing or checking rituals) ([Mataix-Cols et al. 2010](#); [Pertusa et al. 2010](#)).

In OCD, the behavior is generally unwanted and highly distressing, and the individual experiences no pleasure or reward from it. Excessive acquisition is usually not present; if excessive acquisition is present, items are acquired because of a specific obsession (e.g., the need to buy items that have been accidentally touched in order to avoid contaminating other people), not because of a genuine desire to possess the items. Individuals who hoard in the context of OCD are also more likely to accumulate bizarre items, such as trash, feces, urine, nails, hair, used diapers, or rotten food ([Pertusa et al. 2008](#)). Accumulation of such items is very unusual in hoarding disorder.

When severe hoarding appears concurrently with other typical symptoms of OCD but is judged to be independent from these symptoms, both hoarding disorder and OCD may be diagnosed ([Mataix-Cols et al. 2010](#)).

### ***Neurocognitive disorders***

Hoarding disorder is not diagnosed if the accumulation of objects is judged to be a direct consequence of a degenerative disorder, such as neurocognitive disorder associated with frontotemporal lobar degeneration or Alzheimer's disease. Typically, onset of the accumulating behavior is gradual and follows onset of the

neurocognitive disorder. The accumulating behavior may be accompanied by self-neglect and severe domestic squalor, alongside other neuropsychiatric symptoms, such as disinhibition, gambling, rituals/stereotypies, tics, and self-injurious behaviors ([Snowdon et al. 2012](#)).

## Comorbidity

Approximately 75% of individuals with hoarding disorder have a comorbid mood or anxiety disorder ([Frost et al. 2011b](#)). The most common comorbid conditions are major depressive disorder (up to 50% of cases), social anxiety disorder (social phobia), and generalized anxiety disorder ([Frost et al. 2011b](#); [Pertusa et al. 2008](#)). Approximately 20% of individuals with hoarding disorder also have symptoms that meet diagnostic criteria for OCD ([Frost et al. 2011b](#)). These comorbidities may often be the main reason for consultation, because individuals are unlikely to spontaneously report hoarding symptoms, and these symptoms are often not asked about in routine clinical interviews.

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