

# Hoarding Disorder: Information for Primary Care



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**Summary:** Hoarding disorder is a common yet under-recognized condition that can cause significant problems. While collecting things is a human trait, in some individuals it becomes an extreme, to the point where it causes significant stress to the hoarder and to family and friends. At the extreme of consequences, hoarding behaviours can lead to death, e.g. one quarter of preventable fires are due to homes which have become full of hoarded, (flammable) possessions and materials. Treatment can help improve the quality of life of the patient, and allow him/her to stay at home. Interventions include counseling and interdisciplinary care. There are no medications per se for hoarding behavior per se, however if there are associated conditions such as depression, anxiety, OCD, then treating these may help alleviate hoarding behaviours.

## Case

J. is a 50-yo male, single and living in an apartment. You know both him and his wife as your patients, though his wife passed away a few years ago. He doesn't come regularly for checkups. Today, he comes to the clinic accompanied by his adult daughter. His daughter expresses her concern that ever since her mother passed away, her father is simply not taking care of himself, and that the apartment has become cluttered and unliveable. While his wife was still living, she used to help ensure that things didn't get too out of control. Now that his wife has passed away, he just accumulates things and can't get rid of anything.... His daughter says, "There is stuff piled to the ceilings, and there is no room to move. You literally have to climb over things to get from place to place.... I'm worried he could fall, get trapped, or have a pile of things collapse on him! You have to do something!"

## What is it?

- Hoarding disorder is characterized by:
  - Persistent difficulty discarding or parting with possessions
  - Harmful effects—emotional, physical, social, financial, and even legal—for the person suffering from the disorder and family members.
- While the individual that is hoarding may not be concerned about their hoarding, the hoarding can be very concerning to others, such as family members, or landlords.
- Hoarding is not the same as normal collecting behaviours
  - In hoarding, the quantity of their collected items is much greater than in collecting; hoarders accumulate a large number of possessions that often fill up or clutter active living areas of the home or workplace to the extent that those areas can no longer be used normally.

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## Epidemiology

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- Prevalence 2-5% (DSM-5)
- Note that although it is underrecognized, it does occur at twice the rate of obsessive-compulsive disorder (OCD) (2%) and at almost 4 times the rate of bipolar disorder and schizophrenia (Pertusa, 2010).

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## Clinical Presentation

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- Individuals with pathologic hoarding do not usually voluntarily seek help from a physician.
- Many times, it may be other family members that report concerns to the family physician.
- In elderly patients with pathologic hoarding, it is often through an event such as a fall or fire that they come to the attention of family members, neighbours and professionals.

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## History / Interviewing

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Typical screening questions based on DSM-5 might be the following:

- Do you tend to keep things that others would get rid of?
- Do you have problems getting rid of things?
- Does this cause problems at home? For example, are you unable to use any rooms because they are full of stuff?
- Does it cause problems with other family members?
- Do you tend to collect free things? Do you tend to buy more things than you can use or afford?

### Risk Assessment

The diagnostic interview (ideally with collateral history from others) can include an assessment of risks caused by the hoarding such as:

- Potential fire hazards
- Risk of a clutter avalanche
- Any rodents or insects?
- Are the living conditions unsanitary or unclean such that they pose a risk to health?
- Are there other people affected in the home, e.g. children, elderly?
- Are there animals in the home?

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## DSM-5 Diagnostic Criteria

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DSM-5 Criteria for Hoarding Disorder:

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, or the authorities).
4. The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning (including maintaining a safe environment safe for oneself or 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 (OCD), decreased energy in major depressive disorder, etc.).

## Differences with DSM-IV and DSM-5

In the DSM-IV, hoarding was not recognized as a distinct disorder, but rather as a symptom that could occur in conditions such as obsessive compulsive disorder (OCD). Now however, it is realized that hoarding disorder has its own particular symptoms, prognosis and treatment course, which is why it is recognized as a separate condition in the DSM-5.

## Differential Diagnosis (DDx)

Hoarding of objects comprises a continuum from normality to extreme disease.

Differential diagnosis of hoarding behaviours:

Normal hoarding, i.e. collecting	The hoarding behavior may in fact be normal, if it is not causing any impairment. Many people enjoy collecting comics, hockey cards, coins and stamps. Collecting is a normal phenomenon, where the goal is to organize and enjoy a series of objects.
Depression	Hoarding (along with self-neglect) can be secondary to depression. Treating the depression then leads to improvement of the hoarding behaviours.
Dementia	Dementia particularly frontotemporal lobar degeneration (FTLD) Red flags for hoarding due to dementia <ul style="list-style-type: none"> <li>• Onset later in life</li> <li>• Passive rather than active accumulation of items (eg, failure to take out the garbage or recycling, stacking old newspapers)</li> <li>• Cognitive impairments (e.g., short-term memory loss, long-term memory loss on testing)</li> <li>• Memory loss (e.g. medication non-adherence; neglecting medical, dental, and other important appointments)</li> <li>• Overvalued ideas, delusional thinking, and hallucinations (including visual and auditory)</li> <li>• Loss of function with activities of daily living (e.g. hygiene, dressing) or instrumental activities of daily living (e.g. driving, shopping)</li> <li>• Alcohol, medication, or other substance misuse</li> <li>• New or progressive sensory impairments (eg, vision and smell)</li> <li>• New or progressive CNS disease (eg, stroke, Parkinson disease)</li> </ul>
Brain injury	Brain injuries can lead to cognitive issues that can then lead to hoarding behaviours.
Anxiety disorders	Such as social anxiety disorder, generalized anxiety disorder, and classically, obsessive compulsive disorder (OCD)
Substance Use	Individuals with substance use may neglect personal care as well as their surroundings, and may thus appear to have hoarding.
Schizophrenia	Individuals with schizophrenia can have hoarding behaviours.

## Comorbid Diagnoses

People with hoarding disorder are at risk of having comorbid conditions such as:

- Major depressive disorder (MDD)
- Acquisition-related impulse control disorders
  - Compulsive buying
  - Kleptomania
  - Acquiring free things
- Anxiety disorders
  - Social anxiety disorder (aka social phobia)
  - Generalized anxiety disorder (GAD)
  - OCD: Note that although OCD can be seen with individuals with hoarding, OCD is actually less

common than social anxiety in those with hoarding

- ADHD, Inattentive Type

## Physical Exam (Px)

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Physical exam is useful to rule out other medical conditions that may contribute to the hoarding behavior, such as dementia.

## Investigations

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There are no pathognomonic tests to diagnose hoarding disorder, however laboratory investigations may be helpful to rule out associated medical conditions.

## Management in Primary Care

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- Goals of treatment
  - Help patients to remain safely at home (unless severe risk or incapacity)
    - Most patients have this goal, and thus, the goal of being able to stay safely at home can be something to agree upon
  - Decreasing social isolation
  - Reducing excess clutter, ideally in a stepwise approach
- Refer to community resources
  - Treatment of hoarding disorder is generally a multidisciplinary approach relying on other community supports and services
  - Are there animals at risk? Contact the Humane Society or SPCA
  - Are there children at risk? Contact child welfare agencies such as Children's Aid Society (CAS), etc.
- Refer to local specialists in hoarding

## Management in Primary Care: Medication Treatment

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- There is no medication per se that treats hoarding
- However, if there are conditions such as anxiety, depression, psychosis, OCD then those can be treated
  - E.g. if social anxiety, depression or OCD, then consider SSRIs or SNRIs
  - E.g. if psychosis, then consider antipsychotic medication

## When to Refer

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In most cases of hoarding, specialized supports from mental health professionals and/or specialized hoarding resources are required.

## Who to Refer to

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- Public health:
  - Depending on the community, the local public health department may offer services, or help with navigating services. Hoarding is a public health issue, because due to the increased of fires, insect and rodent infestation, it affects more than just the individual with hoarding.
- Mental health professionals:
  - There may be mental health professionals in the community that have expertise with hoarding, which may include social workers, counsellors and psychologists.
- Specialized hoarding services exist in many communities, which may include:
  - Cleaning companies

- Individuals with expertise in helping with clutter
  - Although there are many services which purport to help with hoarding, if at all possible, it is best to choose a professional that belongs to a professionally regulated profession, e.g. social work, nursing, psychology, etc.

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## About this Document

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