

## **Talking points for hoarding disorder PSA from the Western Mass Hoarding Disorder Resource Network by Becca Belofsky & Lee Shuer (2021)**

**May is Mental Health Awareness Month. Join us in sharing this info and inviting folks to reach out for help. Thank you!**

**Hoarding Disorder is a diagnosable, treatable mental health challenge.** 2% to 6% of the United States population struggles with it ---that's roughly 6 million to 16 million people who could use help. Clutter is only the visible part of the struggle. The underlying causes are much greater for the individual than meets the eye. Calling people "messy, lazy, crazy" or the like is not only hurtful, but it's unhelpful, too. We want to welcome people to good help, not drive them away, or further isolate them.

**The word "hoarder" is often associated with negative stereotypes, and most people living with HD don't like the term.** When talking to, or about people who have too much stuff, try to eliminate this word. Hoarding is a behavior, not an identity. If you're talking to someone who has too much stuff, we suggest using the language that they use to address their behaviors. That said, if they self-refer as a hoarder, then we would too. If you're speaking generally about people with a diagnosis of HD, we suggest terms like, "living with HD," "over-collecting," and, "finder/keeper," "archivist," or "artist." These are terms that people with the diagnosis have identified more closely with.

**HD affects all members of a household.** Care and support must be extended to the entire family. Children, both young and grown, need help too. We cannot expect the children of parents with HD to help them with their mental health challenge. They must be seen and heard and relieved of the burden of the caretaker role and receive support too. Spouses also need support relevant to their perspective in the household. They often become the de facto helper and can lose their own feelings of identity in the process.

**Many people with HD do acknowledge their challenge, and they do want help.** A common misperception is that people with HD always lack insight and refuse to admit that their attachment to possessions is a problem. Every year, thousands of people make progress in managing their collections. Whether the help is offered by peers or clinical practitioners, people do seek support and do benefit. Every day we have the pleasure of welcoming people to the journey that is recovery and healthier, happier living.

**Stigma towards people with HD is not diminishing.** As masses of people picked the shelves clean of masks, cleaning supplies and other essential goods, the word "hoarder" started making the rounds again. People with HD were suddenly lumped in with people who intended to stockpile and re-sell their items for a profit, which is a crime. The shame and guilt cast by throwing the word around are barriers to people asking for help. HD is not a crime.

**Cleanouts don't work** Removing items from someone's home doesn't make them better, it often makes matters worse. The recidivism rate for refilling the space is quite high. Clearing out possessions will likely damage relationships, especially if items are thrown away without permission.

**It doesn't matter what's collected. People keep all kinds of things.** The diagnosis of HD does not hinge upon the assumed value of the items saved. Too much of anything can become a problem. It is unhelpful to assume that people with HD only keep things that are worthless, worn-out, or useless. Additionally, squalor (aka DEN- domestic environmental neglect) isn't always present in the home of a person with HD, though that doesn't mean there aren't significant safety concerns in some instances.

**People with too many animals are usually overwhelmed caregivers.** People who are called "animal hoarders" may act out of a fear that their animals will be euthanized if they are discovered. Working to decrease this fear and build a bridge between animal lovers and animal welfare organizations may help to save the lives of both the animals and the people who love them. Animal control officers often work with folks to manage the numbers and wellbeing in a way that doesn't do further harm and preserves a positive working relationship.

**HD doesn't discriminate.** People of all ages, races, religions, socioeconomic statuses, and genders are vulnerable.

**It's never too soon or too late to get help.** Most people seek and or receive help for HD in their mid-fifties, but that's not the only time that people can benefit from support. Research shows that people across the lifespan can and do recover from HD. There's no need for folks to wait until they're entirely overwhelmed to reach out! Our hope is that by decreasing stigma, we'll help people feel more comfortable about asking for assistance.

**Peers can help each other.** Research shows that self-help groups facilitated by people with lived experience of HD are just as effective as those run by clinicians.

**Safety first.** Regardless of the cause of an individual's cluttering, their safety and that of people who live with and near them needs to be addressed. The process of making a home safer can be approached systematically. Blocked doors, non-functioning facilities, and tripping and fire hazards must be mitigated. Referring to changes that need to be made in the home environment are likely more acceptable than focusing on changes that may be made within the individual.

**Just because you have a lot of shoes doesn't mean that you have HD.** The diagnosis of HD has more to do with the challenge of letting items go than the compulsion to acquire. Though many people say they can't resist a bargain, they are able to set a limit and discard less desirable possessions to make room for them. There is no "spectrum" of HD. People either have the diagnosis or they don't. To say that you're "kind of a hoarder" is like saying that you're "kind of OCD" because you like to keep your desk very organized. People with HD will not feel better just because more people call themselves "hoarders."

**Being in recovery doesn't mean you have to let go of everything.** Many people with HD are reluctant to engage in treatment because they anticipate being told to “get rid of everything.” Most people feel more comfortable and are more likely to engage in recovery practices if they focus on keeping a reasonable amount of their favorite items and arranging them in such a way that they don't create safety hazards. The inherent safety of items and how they are arranged is what is most important.

**People who struggle with HD often live with other mental health challenges that make recovery more difficult.** Half of people with HD have experienced trauma. 75% struggle with diagnosis including depression, anxiety, and ADHD.

**People with HD are a “protected class” under the Fair Housing Act in the United States.** If a person is at risk of eviction due to clutter-related safety hazards, they have the right to request reasonable accommodations to make their dwelling safer. They may be given more time and/or resources to make these corrections. Though the Fair Housing Act doesn't guarantee that people with HD won't be evicted, it does increase the likelihood that tenancy will be preserved if they demonstrate a commitment to meeting health and safety codes.

Thank you for assisting us in getting this message out!