Clutter and Hoarding

In 2003, an interdisciplinary **New York City Hoarding Task Force** was convened to address the complex behavioral disorder of hoarding in older adults and to develop practical tools and resources for community service providers.

As our population ages, hoarding has been increasingly recognized as a complex mental health problem that threatens the health, safety, and dignity of older adults. Although compulsive hoarding usually starts in young adulthood, it becomes particularly problematic later in life due to increased fall and fire risk. Moreover, the majority of older adults have multiple chronic health conditions, but necessary home care services may be denied until hoarding is resolved. Medicines can be buried under mounds of paper or clutter, and asthmatic conditions are exacerbated by dust and mold. Further, if the spouse dies who has been responsible for maintaining the home or if a person with advanced dementia loses the ability to organize or make rational judgments, then hoarding can spiral out of control.

A recent poll of ten Manhattan community service agencies that serve older adults revealed that approximately 10% of their clients are afflicted with hoarding behavior. Social workers reported of clients who lived in environments with

- Beds and bathtubs so filled with belongings there was no room for sleeping or bathing
- Kitchens that were unsafe and unusable due to cluttered stoves, sinks, and tabletops
- Large amounts of combustible materials blocking walking paths, radiators and fire exits
- No working toilets, sinks, heating and cooling appliances afraid of eviction, they failed to get needed repairs
- Mounds of trash, rotten food, human and animal waste
- Insect and rodent infestation
- Many unkempt pets in need of care

These life-safety, quality-of-life and health issues not only affect the occupants but their neighbors as well. What makes hoarding so challenging is that people who hoard are usually oblivious to the problem and resist intervention. Factors such as extreme emotional attachment to possessions (including what appears to outsiders as useless junk), fear of loss, and the inability to discriminate (trash mixed with valuables) makes discarding items almost impossible.

Without a proper understanding of the psychosocial issues and reasons for hoarding, forced clean-outs, which can be costly, are often unsuccessful: dwellings revert back to an uninhabitable level within a relatively short period of time. Additionally, older adults may experience catastrophic emotional responses during forced cleanouts *requiring emergency psychiatric care*.

Understanding the reasons people hoard can help promote more therapeutic interventions, including on-going support and maintenance. It is our goal that the information contained in this section will help community agencies have a better understanding of, and more compassionate treatment for, older adults with hoarding behavior.

Best Practices

Top 20 Decluttering Tips

1. Let go of ideal notions of cleanliness. Your client may value items that appear to you as worthless or be rubbish. Parting with their belongings (even used paper cups) can cause severe emotional distress.

2. Listen to your client's ideas and plans for their belongings. Explore their hopes, both realistic and unrealistic, and accommodate them if possible. Clients have been helped to donate or sell their belongings. One woman even sent her "stuff" to relatives in her home country.

3. Work at the client's pace if you can. Start with short periods of time. Some clients cannot tolerate even a half hour in the beginning. Keep in mind, though, that a client's decluttering pace is usually slower than the eviction process.

4. Partner with a legal group, home care or nursing agency to find out what level of cleanliness your client needs to achieve in order to attain their goal, whether it be eviction prevention or home care services. You have to meet certain standards, but you *don't* have to exceed them.

5. Focus on fall prevention. Create pathways free of debris, loose cords or slippery rugs. Some frail clients hold onto furniture or other items while moving through the home; ask how your client gets around and preserve their "props" until other assistive devices (canes, walkers) can be introduced.

6. Focus on fire prevention. Make sure your client has a smoke alarm and test it monthly. Red flags include newspapers stored on top of or inside a gas stove or near working radiators. Help relocate their belongings from a hazardous area to a safe place.

7. Be creative and negotiate. Perhaps the client can keep the previous year's copy of a particular magazine, but throw away the prior twenty years' collection. Consider photographing belongings, as this may help the client part with them and preserve memories.

8. Begin by reorganizing, if time allows. Start with a small corner of a room, a single table, or just a section of the table.

9. Ask your client what they would like to do that currently they cannot do because of the clutter. For example, "Would you like us to help you to figure out how you can cook again?" or "How could you do this differently so you can use the stove?"

10. Motivate your client by helping them be realistic. Some clients will declutter only if told they face eviction or cannot be discharged home after a hospitalization. Gentle but firm pressure is appropriate if a client's home or health are at stake.

11. Create a limited number of categories for belongings. Large plastic crates or wicker baskets can help separate items into these categories.

12. Be resourceful in finding workers. Volunteers and other informal supports have been used with success, such as hired high school students who pack up agreed upon donations.

13. Have a social worker present during a major cleanout, preferably one who already has a supportive relationship with the client. Clean-outs can be overwhelming to people with severe hoarding behavior. Have a back-up plan in case emergency psychiatric services are needed.

14. Discuss how to safeguard valuables in the cleaning process. Have a written contract. Agree on what to do with valuables that turn up, such as money, jewelry, checks, bonds, stock certificates, collectibles.

15. Call the ASPCA if you need help finding a temporary or permanent home for pets while the cleanout is being conducted.

16. Consider relocating an individual to a new apartment if the clutter is the result of physical or mental frailty. A new environment can provide a fresh start and enable the client to receive needed services sooner.

17. Encourage the client to participate even during a major cleanout. Get them involved so they can be part of the process and have some level of control. Ask them if you can help find something they might be looking for, or give them a box to help sort through.

18. Plan for a carefully orchestrated clean-up which can result in decreased client anxiety. Make sure you make arrangements

- with the building for entrance and egress when removing possessions and trash
- for use of the elevators
- for cost, rental and removal of dumpsters (**Do not** leave a dumpster or trash bags on the property after a cleanout, even overnight)
- for storage if needed, including cost of transportation to storage facility

19. Communication is Vital. It is important for the client to communicate with the cleaning crew - making their concerns known. If the crew doesn't speak the same language as the client, there should be a supervisor/translator/advocate present so that the client can make his/her needs known and can feel as if he/she has some control over the situation.

20. Plan for on-going maintenance and supervision to maintain a decluttered environment.

Best Practices Working With Individuals With Dementia Who Rummage and Hoard

People with dementia experience memory loss, mental confusion, disorientation, impaired judgment and behavioral changes, which may include rummaging and hoarding. The following information may be helpful to you when working with individuals who are experiencing these symptoms.

Rummaging

People with dementia may spend excessive amounts of time rummaging through their possessions. This may happen because they are searching for items they have misplaced or hidden. Oftentimes, people with dementia hide their possessions, forget where they have hidden them, and then blame others for stealing them.

Rummaging behavior may also result from boredom as people with dementia find it difficult to initiate activities and rely on others to keep them active. Quite often, redirecting individuals to activities that they enjoy, such as music, gardening, and/or meal preparation, can help distract them from engaging in distressing behaviors. For individuals in the later stages of dementia, certain repetitious activities, such as folding napkins or sorting colored socks, can satisfy the need to be active and engaged.

Hoarding

Some people will hoard or save numerous items, including dirty clothes, food, and papers. Keep in mind that individuals with dementia are continuously losing parts of their lives. Losing a meaningful role in life, an income, friends, family, and a good memory can have an impact on a person's need to hoard and or to "keep things safe". Hoarding in this population is oftentimes triggered by the fear of being robbed.

When working with persons who have dementia, it is essential that you keep their safety in mind as they become increasingly unable to protect themselves. Order, routine and simplicity are most helpful and a house or apartment that is relatively uncluttered is the ideal environment.

Tips to Consider

- 1. **Building trust** Any changes you make in the home of a person with dementia could cause the person to become very anxious and agitated. It is essential, therefore, that you build a sense of trust between yourself and your client before you attempt to make any changes at all.
- 2. **Focus on fire prevention** Check for papers stored on top of or inside a stove or microwave, and near working radiators. Make certain your client has a working smoke alarm and arrange for someone to test it monthly.
- 3. **Focus on preventing poisonous ingestion** Be aware that people with dementia may not recognize that some things are not good to eat. Keep potentially dangerous materials such as cleaning fluids, plant soil, lotions, and medicines out of reach. Check the refrigerator on a regular basis to make sure that rotten food is thrown away.
- 4. **Focus on fall prevention** Make certain that pathways are clear and that there are no slippery rugs that could cause falls. Keep in mind that some frail adults hold onto furniture while moving through the home. Observe how your client gets around and make sure that these supports are stable.
- 5. **Minimize the number of hiding places** by locking unused closets or doors Put signs that say "NO" or "STOP" on places that you want the person to stay out of. Note: This may not work for people who are advanced in the illness.
- 6. **Limit the amount of valuables** or cash that are within reach of the person with dementia.
- 7. **Keep the amount of junk mail to a minimum** so the person has less to manage. If possible, arrange for bills to be sent to some one else for payment.
- 8. **Remove non-essentials** such as out of season clothing to lessen the amount of clutter. Remember, however, that a person with dementia will experience increased anxiety if she/he believes that these possessions have been stolen.
- 9. **Understand coping mechanisms** For example, some people with dementia keep their belongings, including clothing, out in the open otherwise they forget where they have placed them. This coping mechanism, with oversight by a caregiver, may help a person continue to function in the beginning or middle stages of the disease. Other individuals may be willing to put their belongings away if large signs or labels, such as "Socks" or "Blouses" help them identify the location of their possessions.
- 10. Fill a drawer full of "odds and ends" for the person to enjoy rummaging through.
- 11. Check wastebaskets for "lost" items before they are emptied.
- 12. **Provide support** such as home care for on-going maintenance.

- 13. **Learn their hiding places** If a person hides things, learning where their favorite hiding places are will help you locate their important items. Items are often put in the same places, such as under carpets or mattresses and in shoes, handbags, coat pockets, or drawers.
- 14. **Keep duplicates of important items** such as glasses, hearing aids, keys, etc. as back-up. Have the client's doctor's name on hand if duplicate prescriptions need to be filled.
- 15. **Remove discarded items immediately** If you are removing items from your client's home, it is best to remove them immediately from the premises or your client may rummage through the garbage and bring them back into the house.

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Hoarding Task Force

The first seminar on Hoarding was sponsored by the <u>Hoarding Task Force</u> on January 21 at Cardozo Law School. The seminar was attended by Social Workers, Property Owners and Landlord-Tenant attorneys. The seminar presented the findings of the task force, which was formed last year to deal with the unique situation of clutter in apartments with long-term renters.

Most people are familiar with famous case of the Collyer Brothers, who were both found dead in their Harlem Brownstone, buried under their own extensive collection of junk. However, this syndrome, known as compulsive hoarding can take many forms, less extreme than the Collyers- it is a growing concern as the New York City population ages. Rent regulation was acknowledged as a factor of the hoarding cases in the City due to the length of time people remain in apartments.

Compulsive hoarding has many dimensions; when a person becomes emotionally attached to objects and cannot part with them or when a person collects multiple items that others have discarded. The reasons for hoarding can be varied and may be exacerbated by both mental illness and the aging process. Previously, Property Owners with these situations had no choice but to commence costly legal proceedings.

The Hoarding Task Force has developed an intervention protocol which allows Owners to use the services of various Social Service Agencies to work with the Tenant in an attempt to control the behavior prior to commencing eviction proceedings.

Information regarding local contacts and Social Service Agencies is now available through the <u>Hoarding</u> <u>Task Force</u> website, <u>http://www.cornellaging.com/gem/hoarding_index.html</u>