

## Managing hoarding and squalor

**Author:**

Gleason, A; Perkes, D; Wand, APF

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# Managing hoarding and squalor

## SUMMARY

Hoarding and squalor are complex conditions with a range of physical and mental comorbidities.

GPs play a key role in identifying people who experience these conditions, screening for safety risks, referral to specialist services and encouraging people to accept treatment and ongoing monitoring. Treatment for contributing and comorbid conditions should be optimised, with the help of specialist services when required. Medicines should be reviewed and adherence confirmed.

For moderate to severe hoarding and squalor, referral to specialist psychiatry, geriatrics and allied health services is recommended for thorough assessment, treatment of underlying conditions and ongoing management.

## Introduction

Hoarding and squalor are complex conditions with diverse underlying aetiologies. In both conditions there is an accumulation of possessions or rubbish. Intervention is recommended due to a risk to the health and safety of the individual or others.

Although hoarding and squalor can at times appear similar in the home environment, they are two different, albeit sometimes overlapping, conditions. Hoarding disorder is a mental illness whereas squalor describes an unsanitary living environment, which may be the end result of extreme domestic neglect or hoarding.<sup>1,2</sup> A quarter of people with hoarding and squalor have a physical health problem that contributes to the state of their living environment, such as incontinence, immobility, or severe visual impairment.<sup>3</sup>

Hoarding and squalor can pose safety risks to the individual, other household occupants, pets and neighbours.<sup>4,5</sup> People who hoard, and other household members, have been found dead after being trapped by falling items. Accumulated objects increase the risk of falls, and insect or rodent infestations lead to health hazards.<sup>5</sup> The risk of fire and associated mortality is high.<sup>6</sup>

## Hoarding

Hoarding becomes a disorder when it is excessive, reduces usable living space and interferes with people's lives.<sup>7</sup> A central feature is the accumulation of possessions due to difficulty discarding them related to distress, as opposed to poor motivation or unawareness concerning the need to discard.<sup>3</sup> Hoarding disorder can occur in the absence of another physical or mental disorder and is a distinct diagnosis in DSM-5 (Box 1).<sup>8</sup> Hoarding behaviour can also occur in association with various medical conditions (Box 2).<sup>9</sup>

### Box 1 DSM-5 hoarding disorder – abbreviated diagnostic criteria

- Difficulty discarding or parting with possessions, regardless of their value.
- This difficulty is due to a perceived need to save the items and to distress associated with discarding them.
- The difficulty discarding possessions results in the accumulation of possessions that congest and clutter active living areas and substantially compromises their intended use.
- The hoarding causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.
- The hoarding is not attributable to another medical condition.

Source: adapted from reference 8 (p. 247)

### Box 2 Conditions in which hoarding behaviour can occur

- Acquired brain injury
- Attention deficit hyperactivity disorder
- Autism spectrum disorder
- Behavioural variant frontotemporal dementia
- Hoarding disorder
- Intellectual disability
- Obsessive compulsive disorder
- Obsessive compulsive personality disorder
- Parkinson's disease/dopamine agonist-associated impulse control disorder
- Prader-Willi syndrome
- Schizophrenia

### Andrew Gleason

Senior staff specialist, Department of Consultation Liaison Psychiatry, Concord Repatriation General Hospital, Sydney

Honorary principal research fellow, Melbourne Dementia Research Centre, Florey Institute of Neuroscience and Mental Health, Melbourne

### Danielle Perkes

Program manager and Senior occupational therapist, Hoarding and Squalor Service, Sydney Local Health District, Mental Health Service, Marrickville Health Centre, Sydney

### Anne PF Wand

Conjoint associate professor, Specialty of Psychiatry, Faculty of Medicine and Health, University of Sydney

Conjoint senior lecturer, Discipline of Psychiatry, School of Medicine, University of NSW, Sydney  
Senior staff specialist, Older Persons' Mental Health, Concord Centre for Mental Health, Sydney

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Hoarding disorder tends to begin early in life and has a chronic, progressive course.<sup>2,10</sup> The prevalence is 1.5–5.8%.<sup>11</sup> Insight is limited in about half of cases.<sup>10</sup>

Approximately half of all people with hoarding disorder are impaired by a current physical health condition. Arthritis and sleep apnoea are common in older people who hoard.<sup>12</sup> Estimates of comorbid mental illness, such as mood, anxiety or attention deficit hyperactivity disorders, range from 56–85%.<sup>11,13</sup> Personality traits of perfectionism, indecisiveness and procrastination are associated with hoarding.<sup>14</sup> People with hoarding disorder often have a low quality of life and poor function.<sup>15</sup> The burden on family members is high.<sup>16</sup>

### Squalor

Severe domestic squalor describes a home that is so unclean, messy and unhygienic that people of a similar culture and background would consider extensive clearing and cleaning essential.<sup>17</sup> This is not a diagnostic entity in current classification systems, but an epiphenomenon of other diagnoses. There are two main pathways to squalor – domestic neglect such as failure to remove rubbish, and hoarding such as excessive accumulation of items.<sup>1</sup>

People living in severe domestic squalor often refuse intervention, withdraw socially and lack insight into their living conditions.<sup>1</sup> About half are over 65 years old, and at least one in a 1000 people over 65 live in squalor.<sup>1,18</sup> Presentation is often precipitated by the loss of a partner, increasing frailty or symptoms of a neurocognitive disorder.<sup>19</sup> Neglect and elder abuse can also be potential factors.<sup>20</sup>

The majority of people living in squalor also have a psychiatric disorder (Box 3),<sup>1</sup> yet only half have had contact with a mental health service in the preceding year.<sup>3</sup> People living in squalor may be malnourished and mortality is high.<sup>21,22</sup>

#### Box 3 Conditions that can lead to squalor

- Vascular cognitive impairment
- Alzheimer's disease
- Frontotemporal dementia
- Acquired brain injury
- Alcohol or other substance misuse
- Depressive disorders
- Bipolar disorder
- Schizophrenia, other psychotic disorders
- Intellectual disability
- Autism spectrum disorder
- Personality disorders

### Cognitive impairment

Cognitive impairment, specifically executive dysfunction (also known as frontal lobe impairment), is almost universal in people living in severe domestic squalor.<sup>18</sup> Executive dysfunction leads to deficits in planning, organisation, abstract reasoning, insight and decision making.<sup>23</sup> Similarly, hoarding is also associated with specific deficits in information processing, particularly attention, memory and executive functioning.<sup>24,25</sup> Hoarding and squalor may both arise from a frontal dysexecutive process.<sup>26</sup>

### Getting help for individuals

It is uncommon for GPs to receive referrals for hoarding and squalor, but it is important for them to be aware of how to screen for the severity of hoarding and squalor along with the risk to safety, and pathways for assessment and referral.

Unless GPs do home visits, it is often not immediately obvious that a patient has hoarding disorder. Hoarding behaviour may first come to light through a variety of sources including neighbours, relatives, service providers, police, fire services, local council and accommodation providers. The person tasked with the initial assessment may be from a general or aged-care health service, mental health, welfare and community services or the local council.<sup>27</sup>

### Assessment

Detailed multidisciplinary assessment is important in moderate to severe cases (Box 4). The team undertaking the initial assessment screens for underlying health issues, evaluates individual needs and can then refer on to specialist services for more targeted assessment and management. The assessment includes:

- the environment and symptom severity (including use of hoarding/clutter and squalor severity-specific tools)
- the person and contributing conditions (mental and physical health, cognition)
- functional impairment due to hoarding or squalor
- safety risks (including readiness for change and assessment of capacity).

### Capacity to refuse treatment

Many people with hoarding disorder or living in squalor lack insight into their condition and refuse treatment.<sup>28</sup> If intervention is needed (because there is a risk to the person's health or to others) but declined, assessment of their capacity to refuse treatment is indicated. Given the high prevalence of executive impairment, it is not acceptable to withhold treatment out of a purported respect for the person's autonomy

Box 4 Principles of assessment of hoarding and squalor<sup>30,33,40</sup>

- **Engagement:** Build trust. Reframe your role in terms of meeting the person's perceived needs.
- **Home visit:** Beforehand, obtain information to identify safety issues.
- **Environment/symptom severity:** Assess the degree of hoarding/squalor and document it – take photos if the person permits, or use validated tools such as the Environmental Cleanliness and Clutter Scale (ECCS), Clutter Image Rating Scale (CIRS), Hoarding Rating Scale (HRS).
- **Contributing conditions:** Assess the factors underlying hoarding/squalor and possible comorbidities:
  - A. **Physical health problems.**
  - B. **Cognitive problems:** Executive function should be assessed. Mini Mental State Exam alone is insufficient and may be normal.
  - C. **Mental health problems:** Assessment and usual treatment of comorbidities may need to be undertaken before or simultaneously, as they may interfere with addressing hoarding. For example, treatment for anxiety may assist with interventions to discard items.
- **Function:** Screen for impact on daily activities. For example, does the person:
  - sleep in their bed
  - have somewhere to sit
  - have a place to prepare food and a place to eat
  - use their toilet, shower, appliances/utilities e.g. fridge, water
  - move throughout the home safely
  - if there was a fire or a need for an ambulance, are the hallways clear?
- **Potential for harm/safety risks:** Assess the consequences of hoarding/squalor:
  - risks to the person themselves (e.g. risk of self-harm/suicide, imminent safety hazards like fire or falls, acute medical illness, ability to receive emergency services in the home)
  - risks to dependents (e.g. children and young people, adults in the household with a disability or frailty, pets)
  - risk of eviction/homelessness
  - medication safety.
- **Legal and ethical issues/capacity:** Assess the person's decision-making capacity in relation to hoarding/squalor. Are there other legal considerations? For example, does the council or another organisation have the power to override the person's wishes? Consider the person's readiness for change, and the safety risks, and capacity to refuse treatment in relation to the risks.
- **Collateral history** should be obtained.

without conducting a capacity assessment.<sup>29</sup> Attempts to engage affected individuals and promote capacity should be maximised. There are three main scenarios:

1. If the person has decision-making capacity but initially refuses assistance, there should be ongoing attempts to engage them. Over time the person may recognise the consequences of this decision and be more receptive towards help. Education and support for relatives are useful in preparation for when a person is ready to accept help or to respect their decision. If there are safety issues regarding the person's living conditions that cannot be addressed voluntarily, referral may be needed.<sup>30</sup>
2. If decision-making capacity cannot be assessed (e.g. the person will not open the door or engage), there are a few options. If there are signs of a mental illness, the person can be referred to a local psychiatric service for assessment. Guardianship legislation may be relevant if there are concerns about serious physical health issues and suspected lack of capacity. Aged Care Assessment Services may assist. Police may be asked to perform a welfare check. In some jurisdictions, local councils can order an inspection. Property inspections may also be conducted under residential tenancy legislation.<sup>30</sup>
3. If the person lacks decision-making capacity and there is a risk to safety or welfare, it may be necessary to appoint a substitute decision-maker or guardian through the local guardianship tribunal. The guardian can make decisions about interventions including medical treatment, services for cleaning and other domestic support, and moving into a residential aged-care facility where applicable. If decision-making incapacity is related to an underlying psychiatric illness, the local Mental Health Act may be more appropriate to enable treatment of the illness, which may lead to the person regaining capacity.<sup>30</sup>

## Management of hoarding and squalor

The majority of evidence for specific management strategies in severe domestic squalor comes from case reports.<sup>1</sup> Management guidelines are consensus based.<sup>1</sup> A summary of interventions to manage hoarding and squalor is provided in Box 5. If another medical or psychiatric condition is the main driver of hoarding, this should be treated first.<sup>1</sup>

### Box 5 Interventions for hoarding and squalor

- **Coordination of services:** they need to work together to deliver a consistent approach. A case manager or key worker should be identified to lead the response. Ideally, there is one coordinated intervention plan across agencies to facilitate collaboration and clear communication (including clear goals, support and timeframes).
- **Match the assessment to specific specialist services and interventions,** including:
  - Treat comorbidity and the underlying causes of the hoarding and squalor.
  - Arrange for community services to support people with functional impairment. Some people may not be able to have their complex or high needs met at home and may need to enter a residential aged-care facility or supported accommodation. Occupational or functional assessment may assist.
  - Arrange for services to assist with cleaning.
  - Consider making a cleaning agreement with the person and actively involve them, where appropriate, to reduce trauma.
  - Arrange or notify services as indicated e.g. Child Protection Services, RSPCA, Ageing and Disability Abuse Helpline.
- **A Team Care Arrangement** may help keep track of the numerous referrals and agencies involved and review outcomes.
- **Support the individual, their carers and relatives.** Interventions are often experienced as very stressful and there may be multiple unsuccessful attempts. When someone is not ready for change, relatives may need support. Resources and strategies for families and carers may be found in the book 'Digging Out' by Michael Tompkins et al.,<sup>31</sup> or online e.g. [Hoarder.org](http://Hoarder.org).
- **Arrange ongoing funding** source (e.g. National Disability Insurance Scheme, My Aged Care), with **ongoing home-visit-based case management and domestic assistance** for support and monitoring to ensure maintenance of treatment gains.

## Non-drug interventions

Cognitive Behavioural Therapy for Hoarding Disorder (CBT-H) reduces disease severity, but functional impairment may persist.<sup>5,32</sup> Therapy should target specific symptoms, such as emotional attachment to items, patterns of avoidance and neuropsychological deficits.<sup>5</sup> Behavioural approaches include:

- goal setting
- training in organising and problem-solving skills
- practice in sorting and discarding, and graded exposure to discarding.<sup>5,33</sup>

Motivational interviewing techniques may be useful.<sup>5</sup> Emerging approaches for moderate to severe hoarding include harm reduction<sup>34</sup> and community-based interventions<sup>35</sup> which focus on safety interventions with multidisciplinary and multi-agency responses.

## Drug treatments

Clinical trials of drug treatments for hoarding disorder are of poor methodological quality but show modest benefit (Table).<sup>36</sup> Open-label trials suggest improvement with paroxetine in obsessive compulsive disorder with hoarding,<sup>37</sup> and with venlafaxine,<sup>38</sup> adjunctive methylphenidate<sup>39</sup> and atomoxetine in hoarding disorder.<sup>40</sup>

## A coordinated approach

GPs, often with established long-term relationships with their patients, can play an important role in both the detection and management of hoarding and squalor (Box 6).<sup>41</sup> A coordinated approach should be provided to ensure the home is safe for the patient, others living in the same residence and any carers (Box 4). This can include developing safety goals with the individual, and regular home-visit support

Table Pharmacotherapy studies for hoarding

| Study                           | Population                                     | Intervention  | Outcome  |
|---------------------------------|--|---|--|
| Saxena, et al <sup>37</sup>     | OCD (n=32 with hoarding, n=47 without)         | Paroxetine (open label, titrated to target dose of 40 mg/day), no other treatment | Both groups improved with no significant differences between groups.<br>Hoarding symptoms improved as much as other OCD symptoms.          |
| Saxena and Sumner <sup>38</sup> | Hoarding disorder (n=24)                       | Venlafaxine (open label, titrated to 150–300 mg/day), no other treatment          | 36% decrease in UCLA Hoarding Severity Scale score, 70% classified as 'responders'   |
| Rodriguez, et al <sup>39</sup>  | Hoarding disorder (n=4), one with comorbid OCD | Methylphenidate (open label, 18–72 mg/day), usual medicines continued             | 2 of the 4 subjects had a modest reduction in hoarding symptoms  |
| Grassi, et al <sup>40</sup>     | Hoarding disorder (n=12)                       | Atomoxetine (open label, flexible dose of 40–80 mg/day)                           | Statistically significant reduction on UCLA Hoarding Severity Scale for the group, 6 classified as 'responders' and 3 'partial responders' |

OCD obsessive compulsive disorder

**Box 6 General practice strategies for hoarding and squalor**

- The general practice role is vital. A couple of questions can encourage a patient to consider making their home safer, receive assistance with their health, or start recovery. GPs can lead or be key advocates for intervention with other providers, making a significant difference in their patient's life.
- GPs can be alert for signs of hoarding and squalor e.g. patients with bags overstuffed or filled with a variety of objects, or problems with personal hygiene. GPs may have established relationships with patients and can connect them with services to address these problems.
- Initial screening in the medical centre or home can inform discussions about needed intervention and this information, with consent, can be shared with other services.
- Provide education on relevant medical complications associated with hoarding or squalor. Motivational interviewing assists readiness for change. Effects on physical health can help with motivation to start to make homes safe and comfortable.
- Collaborate with other service providers to coordinate services and develop a management plan. Where possible share information on the severity and impact on daily activities and function to assist with establishing priorities.

Source: adapted from reference 41

to declutter key areas, motivational interviewing, emotional support, and physical assistance or cleaning if the person is frail. GPs are also well placed to ensure underlying physical and mental health conditions are being managed, and to check on medication adherence, use-by date and storage.

In severe cases, specialised cleaning and pest eradication may be needed, particularly for squalor. Cleaning and decluttering can be distressing. Emotional support, a written cleaning agreement, and a slow clean approach where possible are recommended.<sup>34</sup> One-off cleaning is usually inadequate and does not address excessive acquisition.<sup>42</sup> When a one-off clean has occurred, a thorough ongoing management plan should be developed including follow-up and support to prevent recurrence, such as ongoing home-based case management, community treatment orders for underlying mental illness, and monitoring by GPs and other health professionals.<sup>30</sup> Where possible, the management plan should be shared across services to prevent or reduce the likelihood of recurrence or deterioration in mental health.

Some non-governmental organisations in Australia, such as Catholic Healthcare, have hoarding and squalor

programs and support groups (e.g. [hsru.com.au](http://hsru.com.au)). Some allied health professionals such as occupational therapists, social workers and psychologists identify as having specialist skills in hoarding and squalor. Private allied health professionals can provide specific programs for hoarding and squalor, particularly when the person has a funding source, such as under a National Disability Insurance Scheme or My Aged Care package in Australia.

## Conclusion

Severe hoarding disorder and squalor are complex and challenging to manage. These conditions can often be debilitating for a person and their family. Health workers and people from social services who provide care often feel overwhelmed. Hoarding and squalor can lead to violation of health, housing and sanitation laws. A multiservice, multidisciplinary approach is often required. Medical, social and ethical dimensions need to be considered, and ideally clinical and environmental assessments should occur. ◀

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