

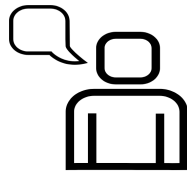
# What Is Hoarding Disorder (HD)?



People with HD save items that others may view as worthless.

They also have difficulty organising what to keep and what to let go of.

Hoarding leads to clutter that disrupts their ability to function in their work and living space.



"What is so noticeable is that hoarding disorder does not have a strong voice. The plight of the HD person, or any partner, child or pet in the overwhelmed household is largely unknown. There are no family meals at a table, no place to study or play, garbage bins rarely used, hardly ever a visitor, and the environment for pets is neglectful" (Mogan, 2018).

## Sources of Hope: The Patient Voice: Observations from individuals suffering from Hoarding Disorder

The 'Sources of Hope' clinical report highlights responses from 10 hoarders about their personal experiences of HD disorder. They share their thoughts on ways to counter the triggers for hoarding, to decrease anxiety, and to improve self-esteem.

*"Doing something each day to reduce clutter – this helps me."*

*"I've realised the most helpful thing someone could do is to be completely non-judgemental (about the chaos), and not suggest I should be getting rid of stuff."*

*"Section off a time for decluttering, otherwise it just feels overwhelming – take it one step at a time."*

*"I am often unable to make up my mind, so yes I am indecisive. To counter this tendency, I have practiced deciding, so I can now do it better."*



See below to read the full report and responses from the HD sufferers.



The popular press depicts hoarding and clutter from the extremes of a house loaded to the gunnels with disorganized piles of clothing, books and furniture to the Japanese expert Kondo arranging cotton tops with exquisite folding techniques or thanking an item, about to be discarded, for its years of service. Somewhere on this spectrum are the symptoms of the serious mental health issue known as Hoarding Disorder (HD). This is a long overlooked condition that has only recently been included in the DSM5 guide that categorises the formal features of psychological disorders. The features of the condition, the circumstances in which it occurs and the particular beliefs and behaviours that make it difficult to treat are gradually emerging in clinical settings and scientific publications. In turn, these findings lead to treatment manuals and new research findings that guide clinicians and caseworkers in their direct work with people with hoarding behaviours and those close to them. What is so noticeable is that hoarding disorder does not have a strong voice. The plight of the HD person, or any partner, child or pet in the overwhelmed household is largely unknown. There are no family meals at a table, no place to study or play, garbage bins rarely used, hardly ever a visitor, and the environment for pets is neglectful.

This is a clinical report on the collaboration between a woman who identifies as having HD, other members in a group who also identify as having HD, and the psychologist group facilitator. Their aim was to convert personal experience of this disorder into practical aids to self-improvement for themselves and other sufferers, and to improve their quality of life so affected by HD and associated symptoms. The project was triggered by a presentation to the group of major predictors of the severity of HD arising from a recent research into the characteristics of hoarding, and published recently (Kyrios, Mogan et al., 2018). Predictors of HD included:

- Certain strong beliefs about things - their value, their sense of attachment to and responsibility for their things, and need to control their things;
- Perceived sense of a lack of warmth in their early family life;
- Difficulty in making decisions.
- Other particular features in the people with hoarding disorder included the need to keep possessions in view, and some issues with memory like low confidence in their memory, and feeling very negative about forgetting.

## **Purpose**

The co-author of this paper found these ideas confronting so she decided to review with other members some factors that might provide those suffering from HD with sources of hope for change.

## **Method**

Individuals in a voluntary hoarding support group were invited to contribute to a study of patient responses in relation to their own experience of hoarding therapy. The following questions were asked of the participants:

### *Causation*

*Q1 What would you say was the trigger for your hoarding?*

*Q 2 Many people with hoarding describe their family of origin as 'cool' emotionally, or expressing a lack of warmth. How does that sound in your case?*

### *Manifestations*

*Q 3 Some people with hoarding described themselves as needing control over their anxiety about objects, being indecisive and being perfectionistic? Does that sound right to you?*

### *Therapy*

*Q 4 As far as 'sources of hope' in improving your own life, your own 'inspirations' towards helping yourself, what would you have liked to hear early on, or would like to tell others having a problem with hoarding?*

These questions aimed first, at what triggered their hoarding behaviour, secondly, to ask about the level of warmth they recalled in the family they grew up with, thirdly, to identify what hoarding meant to them personally, and finally, to probe their personal responses to what research says about hoarding disorder overall.

The comments are reported verbatim. Editing comments have been added in brackets as illustrated for example in the following edited quote, "...leading [me] to depression and social isolation." Qualitative analysis was performed. 10 participants provided statements about hoarding and their experiences of group therapy.

These questions are consistent with the empirically supported expanded CBT model of Frost and Steketee, Moulding, Nedeljkovic, Kyrios, Osborne and Mogan (2017) that posited that cognitive, interpersonal, attachment, developmental and information-processing variables led to a phenomenon described as *self-in-things* that underpins Hoarding Disorder.

## Results

‘Sources of Hope’ responses from 10 hoarders address some of the common themes in the literature about Hoarding Disorder. Tables below (Tables 1-3) indicate particular sources of hope observed by hoarders. These include ways to counter the triggers for hoarding, to decrease anxiety, and to improve self-esteem. Whilst participants noted that overall anxiety can be countered, it is evident from their reports that taking practical action every day reduces felt anxiety and improves self-esteem, as it decreases isolation and shame by specific tasks of goal-setting, planning and re-focusing attention.

Table 1

*Triggers and severity: Effects of perception of lack of emotional warmth in family*

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*“A source of hope came for me, in that the police helped me to move my things and get a unit to live in. I had left home and was in a relationship for nearly a decade. At times I was bashed and badly mistreated, plus I was down to my lowest level.”*

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*“To improve my own self-esteem, and have a satisfying life, I try to stay conscious of my past so I deliberately try to get help to be confident and courageous enough to be warm to my own family and friends.”*

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*“I don’t blame my parents any more, though. I just try to be as warm as I can to my own family now, so I don’t simply copy my childhood environment for my own children to live in. My children deserve better than I had.”*

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Table 2

*Insights about the features of Hoarding Disorders and related anxieties: Decreasing social phobia and decreasing shame*

1) Acquisition:

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*“Doing something each day to reduce clutter - this helps me.”*

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*“Trying not to buy too many new things.”*

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*“Having too much definitely makes it harder so trying to reduce the clutter regularly helps.”*

*“Bin hire [is] VITAL!!”*

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*“I’m triggered by op-shop cheap sales. [I learnt this from the class exercise in therapy about recognizing hoarding behaviour].”*

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*“Declutter every year, instead of every 10-15 years.”*

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*“[I realise that] my attitude to my possessions overlaps with others’ attitudes – they are my furnishings, bedding, linen, books, crockery, china, cutlery...[just like everybody else].”*

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*“Somehow I have learned that the clear space, in itself, isn’t enough motivation for me to clear up, so I make a clear space on my kitchen bench, and then add a bunch of beautiful flowers there in a vase, as my reward to myself. This improves my self-esteem a lot.”*

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*“I try not to buy things unless I already have room for them, since I like to have a place for each thing in my house. When I buy something, I ask myself “What is the destination?”*

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*“To help me make a labelled system for various areas of my own home, area by area, I have successfully hired sittings with a professional organizer. I’ve done wardrobes, kitchen cupboards, and pantry. Once I’ve done this for an area I feel I am able to organise myself better, and I can throw things out more easily. This keeps the system I have mastered for that area working for me.”*

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*“I never knew until I had hoarding therapy that being anxious changes a person’s perception of any situation. I have now undertaken anti-anxiety therapy to help me practice being bold, confident, and decisive. In the past, social phobia has exacerbated my indecisiveness. Somehow I just can’t easily get myself into a self-assured state of mind. Now I recognize that anxiety can distort my thinking. I can test out my hunches instead of being frightened of them. I have learnt to avoid doing things that might have been limiting my satisfaction in life.”*

*“Some people call this process of group therapy ‘coming out’ of the hoarding closet!”*

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2) Overcoming shame and social phobia:

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*“I’ve realised the most helpful thing someone could do is to be completely non-judgemental (about the chaos), and not suggest I should be getting rid of stuff.”*

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*“In hoarding group, I brought in a small bag of ‘junk’ and did the class exercise. My classifying the contents of even a small bag into ‘keep’, or ‘throw out’, in front of a group who gave me encouraging comments, was a life changing experience for me. I realised that I could discard in front of others, showing that I had a problem, but not feel a permanent, overwhelming embarrassment. In fact, I feel proud that I had the courage to seek help.”*

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*“I know have an affliction that has a major effect on my life. When I hear about the seemingly long list of traits, I feel sad. However, when I think of how much change I have achieved, I feel proud. I have changed a lot. I have more self-confidence, and better self-esteem. My friends have helped me. They don't 'get' hoarding, they say 'just throw things out', but my children too like that I am doing something to improve myself. I think being able to change myself it is good role modelling for them.”*

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3) Adopting a successful survivor self-image:

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*“I am so proud of myself. Being strong I am slowly moving along and achieving my goals with my illness, that is, OCD.”*

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*“My family life experience is of ‘downers’, but I march on.”*

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*“Section off a time for decluttering, otherwise it just feels overwhelming –take it one step at a time.”*

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*“I am learning to develop trust in people.”*

*“[The] grand plan in my mind is that all [problems] that I have will be dealt with [by persisting with my attendance at the ‘hoarding therapy’ group].”*

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*“I intend to sort, throw out some, and keep special things, then hopefully once done, I’ll do it again as some of the ‘KEEP’ things may not be as special the second time around.”*

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*“I like to have people around to my house. I invite those who I like to my own place. I clean up for them because I like them coming over.”*

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*“Whenever my house is cleaned and tidied, it inspires me to do even more in the way of de-cluttering, tidying up, working out systems to improve my organization. I employ someone fortnightly to clean my house. She helps me organize myself. I work to get over the hurdle that it is embarrassing for her to come into my rather untidy house when I am away at work.”*

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*“I have worked on feeling entitled to arrange my house as I wish it to be.”*

#### 4) Indecisiveness:

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*“I am often unable to make up my mind, so yes I am indecisive. To counter this tendency, I have practiced deciding, so I can now do it better. I make decision making easier for myself too by practicing breaking down tasks into very small pieces. I commit myself just do doing a small step first. I try to do this even if I do the step imperfectly. Inching towards a goal is better than feeling stuck in the one place forever and never getting tasks completed.”*

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#### Table 3

##### *Goal setting, self-esteem and stigma*

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*“Just listening to others in the group made me realise that I wasn’t alone. Up until joining the group I’d thought it was ‘just me’. [From the group I’ve gained] some interesting ideas on how to tackle the problem.”*

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*“The past – it’s probably that that led to hoarding - and now I am trying to start again”.*

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*“[I have] plans to recover, [and] I hope to succeed.”*

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*“[The] major help [in coming to the group] so far is seeing photos of another group member’s home. [The photos were] actually [of] a house she had not been able to live in for five years as it was too full of stuff. [My] main point [is that] she was an absolutely lovely woman (who incidentally had a major problem). I had been feeling so [sad as] [before that] I ... felt [that] no-one would even be able to see anything OK about me because of my (lesser) hoarding problem. It helped me to [see that] someone could have great qualities and the problem was not all of the person.”*

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1) Labelling and positive self-talk:

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*“It has been an advantage to me knowing to label myself as ‘a hoarder’; it’s not so bad a label really. It’s helped me know myself, and knowing I was simply born with a cluster of tendencies helps me control my impulses to hoard.”*

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*“I now don’t go ‘op-shopping’, or to ‘sales’ etc. I take a list and try to stick to it and reward myself with a cup of tea before going home if I’ve managed to succeed. I feel that maybe deprivation [and] shortages meant [for me that] ‘nothing [at all should be] wasted’ but [I still had to be somehow] tidy, [and] not excessive. Improving self-esteem.”*

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*“What do I envisage helps me? Building my confidence and sound relations. Dancing, rock and roll for the last 7 years, and ballroom dancing for 1 ½ years. I have done yoga since 1974, and [more recently] did teacher training. Now I teach yoga.”*

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*“Keeping up with my friends.”*

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*“Trying to speak out more and be more of a part in conversations and attempt to be heard more. I used to feel angry [and dispirited] when I was never heard. I still don’t get heard often, but when I try to speak, I feel less angry.”*

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*“One [other] thing that helped years ago (before my house got [as] bad) was that I invited people to dinner once a week. None of this helped my hoarding [directly], but I feel better in myself.”*

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*“Maybe due to my low self-esteem, shame and disgrace, from 55 years on it became a problem, suddenly I did greater collecting. My greatest wish, aim, goal, and hope now is to succeed and have a normal home, and a normal life.”*

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*“After I searched the internet about hoarding, I realised I had an anxiety, self-esteem and a bit of a social phobia problem as well. This was confronting, sad and a relief at the same time. I did some anti-anxiety CBT therapy. I learnt to be aware of my SUDS score while throwing out objects (Subjective Unit of Discomfort Score)! I applied for a new job, and was able to stand up better to a couple of bullies at my work.”*

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## **Discussion**

Contributors broadcast a patient voice in comparison with and in contrast to features described in scientific reports of Hoarding Disorder. It is unsurprising that patient feedback fit with already published frameworks about the overall characteristics of hoarding disorder. It seems however important to highlight the content from those who participate in, and particularly those who gain success from, group therapy for hoarding. As well as directly addressing troublesome hoarding behaviours, group therapy is described by participants as decreasing the sense of stigma, as a source of self-education about Hoarding Disorder; as well as improving self-esteem overall that seems to bring greater sense of control over hoarding behaviours. Another lesson these participants noted was that these measures that address self-esteem, generalized anxiety disorder and depression may be extremely helpful to those seeking recovery from Hoarding Disorder. Treatment programs (including CBT programs) that neglect these non-specific comorbidities might limit their potential for effective outcomes. Participants clearly articulated the needs for strategies to better manage anxiety symptoms, reinforcing these measures in their choice of treatment priorities. These patient narrative reports are consistent with the Moulding study (2017) that recommended adding specific strategies against hopelessness and social isolation to the pioneering CBT treatment program (Tolin, Frost, & Steketee, 2014).

The voice of those who participate in hoarding group therapy adds to our knowledge of the individual experiences of HD. Future systematic studies about the many attributes of individuals who hoard might be enhanced by considering the hope message as expressed by group therapy participants. Whilst self-knowledge is essential, learning about these research-based features risks at the same time creating an overwhelming sense of negativity in some sufferers. There is clearly a need for persistence in both therapists and sufferers to emphasise these 'sources of hope' from the patient group voice, in what is hopefully an optimistic tone, so other sufferers of HD are helped to address their own problems with hoarding in their own lives. There is a strong message from sufferers that they value the sense of trust in each other and their special shared understanding of HD. When considering the broader treatment of this high frequency psychiatric disorder, emphasis on group and community-driven support and therapy might lead to greater support to local government in providing locally-based initiatives that combine the infrastructure of local government, community health and housing groups, service groups and churches in a coordinated community response. There are

current examples where agencies are providing short-term remedial interventions followed up by on-going assistance in organizing and decluttering.

It is important to note that this report only covers the views of one group. This group had strong consistency of format, content and personnel, showing they were committed to finding solutions and self-selected for a degree of optimism. Optimism needs further examination as a factor in therapy, given that group therapy does bring common issues to the surface in an ongoing group process.

This group report emphasises the potentially optimistic aspects of insights into a psychological disorder gained through regular group therapy: it presents qualitative data about the overlap between theoretical models of Hoarding Disorder on the one hand, and the lived experience of sufferers of this disorder on the other. This is a topic of interest not only to therapists, but also to those affected, not only the individuals with HD and their families, but also the social welfare community, those living immediate to the emerging problems of HD, and the broader community.

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