



A Lasting Difference

Working with people who hoard to de-clutter their homes and keep them clear

Background

Most organisations that deal with housing will have come across people whose homes are not just untidy and cluttered but are virtually uninhabitable because of the volume of 'stuff' crammed into the property.

Such compulsive hoarding (definition below) and can have serious consequences for:

- **The individual** – not only is there a risk to the person's own health and safety eg. hoarding rubbish including mouldy food, but also they are likely to become increasingly socially isolated and ostracised. Normal daily living tasks such as washing, sleeping, cooking become increasingly difficult because of the level of clutter. Undertaking any repairs or adaptations to the home is not possible because of limited access so deterioration of the fabric of the property accelerates.
- **Neighbours** - particularly in the case of flats, terraced and semi-detached properties, flea, rat and mice infestation plus fire hazards (eg. hoarding newspapers combined with unsafe wiring) can be a serious concern. General deterioration of the property, such as broken guttering, leaking roof and rotting windows can result in structural problems to adjoining buildings. And at the very least, the poor appearance of the property can affect the value and saleability of neighbouring homes.
- **Service providers** – where a person has a health condition or needs social care support, living in a home that is unsafe for care/ health staff to go into is clearly an obstacle to being able to get the help that is needed.

One not uncommon scenario is that unsanitary conditions result in infestation which triggers complaints from neighbours that in turn lead to intervention by Environmental Health who use their enforcement powers to clear out a property.

Whilst understandable, such clearance action can be traumatic for the occupant and also expensive in the case of home owners, as increasingly Local Authorities are placing charges (amounting to thousands of pounds) on such properties to meet the cost of clearance and enforcement. Furthermore, the action can further fuel conflict with neighbours and ultimately fails to deal with the problem because in no time at all the debris builds up again.

What is Compulsive Hoarding?

The Obsessive Compulsive Foundation (OCF), an American not-for-profit organisation, includes the following definition on its website:

“Compulsive hoarding has been defined as the acquisition of and failure to discard items that appear to be useless or of little value. It is manifested in excessive possessions in the home interfering with the normal use of living space and furniture, and is accompanied by significant interference or distress.

Most often, people with compulsive hoarding hoard common possessions, such as paper (e.g., mail, newspapers), books, clothing, and containers (e.g., boxes, paper and plastic bags). Some individuals hoard garbage or rotten food.”

<http://www.ocfoundation.org/hoarding/questions-answers.php>

Finding another way

The Crisis Support pilot service based in Coventry Care & Repair has been working with an Occupational Therapist (OT) to find a more satisfactory and lasting way to work with compulsive hoarders to stop the cycle of 'clutter/ clearance' by changing the behaviour.

The OT undertook a literature search into compulsive hoarding and treatment of the condition, then developed an approach to modifying the ongoing behaviour of the hoarder using an assessment framework.

This framework has potential for use not only by other OTs but also by Crisis Support services and even, in the absence of any other tools, by a range of housing related support staff, home improvement agencies, and environmental health departments.

The conclusion of the OT was that a home improvement agency would be an ideal location for an OT to work alongside a crisis support officer / specialist caseworker in order to deal more effectively with compulsive hoarding behaviour.

This briefing outlines the key aspects of the Framework and highlights the aspects of the initiative.

Part 1: Creating an Assessment Framework

The Occupation Therapist undertook desk based research into the issue of compulsive hoarding. She then applied this information through working alongside the Crisis Support worker with a client of the Coventry Care & Repair service who had reached the stage of wanting to address the problem of his hoarding.

A framework for assessing a person who compulsively hoards, guiding intervention and goal setting was then devised.

Understanding the Compulsive Hoarder

There are many contributing factors to compulsive hoarding and different individuals may develop the behaviour for a variety of reasons. There are links with a range of psychiatric disorders, mental health problems and also some learning disabilities. The aim of this project was to understand and apply some of the psychological and psychiatric theory concerning the treatment of the condition and to use this to underpin a practical approach to reducing the hoarding behaviour.

A number of specific factors about hoarding were highlighted that the general practitioner might find useful:

- *Hoarders can experience tremendous anxiety about discarding items*
- *They may have an excessive emotional attachment to items and have a different perception about the potential usefulness of items that others perceive as useless*
- *The hoarder may have strong feelings of responsibility about being wasteful if they dispose of items, hence the high level of stress/ distress that clearance can bring about*
- *Looking at their piles of clutter can make some hoarders very anxious and give rise to strong feelings about the need to put possessions in order. Yet they are often unable to impose order on the chaos*

In making an assessment of a situation from an OT perspective the following are considered:

- abilities, strengths and interests of client,
- areas of dysfunction,
- balance of activities of daily living,
- roles or occupations and any major changes that have taken place recently,
- potential for change,
- motivation, and
- the wider environment

The underlying principle of the OTs approach is not to help a client by doing things for them, but by guiding the person to help themselves. Thus with regard to hoarding, the approach is not clear the home for the person, but offer guidance and help to learn strategies and techniques that enable the person to discard items and reduce clutter.

Understanding the Stages

The stages model created is based on work by Maltby et al (2008) who use Cognitive Behaviour Therapy to address hoarding. The model is based on the concept of the person being at different stages with regard to recognising that there is actually a problem with hoarding and being ready to tackle this. What stage the person has reached determines the approach to addressing the problem.

Stage	Description	How to approach
1. Pre-contemplation Stage	People at this stage are not even considering the possibility of changing their hoarding behaviour, and are truly unaware that they have a problem.	<ul style="list-style-type: none"> ■ Begin with a frank discussion about the amount of clutter in the home compared with the amount of clutter in other people's homes. ■ Begin discussing potential problems that may arise from hoarding. For example, fire, health, or falling risk. ■ Explain how you can help eg. by agreeing a plan of how you can work together to change the hoarding situation
2. Contemplation Stage	People at this stage have some understanding that there is a problem, but they are ambivalent about changing it. They may alternate between saying they want to do something about the problem, and denying that a problem even exists.	<ul style="list-style-type: none"> ■ Discuss non-judgmentally the positive and negative effects of hoarding. ■ Discuss conflicting desires eg. wanting to keep the items but also wanting to be able to invite people into the home. ■ Again explain how you can support them to make changes.
3. Preparation Stage	This is the window of opportunity for change. The person sees that there is a problem and expresses a desire to do something about it.	
4. Action Stage	People are taking actual steps to change their behaviour – discarding items, organising items, preventing incoming clutter.	<ul style="list-style-type: none"> ■ There will be an agreed plan (see below) ■ The practitioner will be in regular contact with the person to ensure that agreed changes are taking place.

Part 2: Application of the Intervention Framework

Having reached the Action Stage the person is now ready to tackle the hoarding problem alongside the practitioner (s).

A few key points:

- Always view the hoarder as an equal partner in the intervention, working alongside them to achieve agreed goals.
- Support the person by guiding them to help themselves.
- Try to use practical tools to encourage and motivate the person through a difficult process eg. use before and after photographs to provide evidence of progress and achievement.

A Plan for Tackling the Clutter

Action	Implementation
Discarding	<p>Reach agreement with the person about which area of the home should be tackled first taking one room at a time.</p> <p>The person will need to learn how to discard things. They will have to make a decision about each item. They can either</p> <ul style="list-style-type: none">■ Discard it■ Keep it or■ Recycle it <p>The practitioner can help to guide the disposal using questions such as <i>“What is the worst thing that could happen if you did not have this item?”</i></p>
Organising	<p>When the person decides that they have an item that they have to keep, they are asked to immediately identify a specific place keep that item and designate a time frame by which it will be done.</p>
Preventing incoming clutter	<ul style="list-style-type: none">■ The person is asked to keep a daily log of every item that they acquire each day.■ The goal is that the overall number of items acquired each day should decrease.

Goal and outcome sheets are used to plan and record each intervention visit/ session based on the above four categories.

A Few More Rules to Agree

- Once an area is free of clutter, it has to be kept that way.

- Encourage the person to use the cleared area for its intended purpose eg. start to sleep in a cleared bedroom instead of on a sofa.
- The client must dispose of the items that they agree to dispose of after every session. *[It is not unusual for the person to retrieve the discarded items and put them back into another part of the home].*
- A homework assignment is agreed for the client eg. to empty the rubbish out of the home every day.
- The person may need help to create a life balance of work, recreation and rest. Support the person to put together a realistic schedule of activities for each day that will include chores and 'homework' that they have to do, also a recreational activity and a reasonable time to go to bed.

Even after the person has completed the clearance plan, ongoing support on at least a weekly basis will usually be necessary to support ongoing 'clutter management'.

Case Study

Mr M is 72. He lives in a mid-terraced house which he owns. The home is severely cluttered and in an unsanitary condition, and he cannot use the rooms for their intended purpose

He has anxiety, depression and S.A.D. Whilst he is able to walk, his mobility is slow, stiff, and poor around the home, potentially due to the level of clutter. He has attended Cognitive Behavioural Therapy in the past, which he states has not helped his situation with the clutter. He attends MIND groups, but does not receive the support at home from them that he could have due to the clutter.

Mr M has been an 'on and off' client with the Home Improvements Agency for about a year with continuous referrals regarding the state of his house. He has had a 'clearout' which distressed him. Some minor works and adaptations to the home (e.g. electrical works) have been completed. However, the hoarding has continued.

Urgent major repairs and adaptations are needed to the home and he has agreed to an equity release loan. With the builders due in a few months it was imperative for intervention to begin to de-clutter the home in a less stressful way and to reduce ongoing hoarding.

Because of the months of contact with the Crisis Support worker, Mr M had reached the 'Preparation Stage' and wanted to do something to change his situation. He agreed to work with the OT to try to address his hoarding behaviour. Six intervention sessions took place.

Outcome

Mr M initially tackled his living room. This was cleared and a new sofa purchased. 6 weeks after the intervention this room was still being maintained and the diary kept. Further work is needed to tackle further rooms.

Part 3: Lessons for the Future

The OT concluded that that by working with the assessment form and applying certain methods & techniques alongside the home improvement agency team improvements in the situation of a compulsive hoarder were made with regard to clearing and *maintaining an improved state* in a part of their home.

On this basis it is suggested that the model is worth further testing and research as a way forward in a neglected area.

Whilst emphasising that there are no easy solutions, the OT notes that the approach 'could offer many multi-disciplinary teams an opportunity to apply it and work with this very difficult condition. Inclusion of OT input in such teams/ applications is recommended.

Home improvement agencies with Crisis Support or specialist caseworkers are noted as an ideal base for such interventions. Critically, such services have a client centred approach, visit people in their own homes, are skilled at building up trust and relationships and can offer practical support and reinforcement eg. physical improvements to the home.

Proviso

It is important to note that this was a small scale trial which needs further research into its application, but for practitioners faced with the difficult task of addressing the serious housing problems resulting from hoarding, it may well be worth considering as a useful approach in some cases.

The OT was clear that the model was not purporting to be a replacement for therapy such as cognitive behaviour therapy (CBT) and recommended that this should be accessed, where available, in applicable cases.

Credit

This Briefing is based on the work carried out by Harriet Edwards during year 3 of her Occupational Therapy Degree course at Coventry University and whilst undertaking a placement with Coventry Orbit Care & Repair Crisis Support project during 2008.

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