

The Hoarding Handbook

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WELCOME

1. Background

Understanding hoarding behaviour

There has been plenty written about chronic hoarding disorder and the psychology that leads people to fill their homes to a level that compromises their safety. I have worked practically in many homes over the last few years and this workbook outlines the view and approach that we take as a unique professional organising service.

The core for my work is understanding that my client's physiology, thoughts and behaviours are all out there to guarantee their survival but that at some point the coping mechanisms turned on them and started to attack their wellbeing.

Hoarding behaviours can be seen as entirely justifiable due to the hard wiring in the brain that says you must build a protective layer and have a winter store for when we were all in caves. Here and now though with central heating, and shopping available 24/7, it is easy to start to see such tendencies as working in overdrive and to be counter-intuitive. It may not be traditional survival items that are being brought in, but the compulsion to follow this natural dopamine trail to be purposeful in acquisition and store seemed to be at the core of many of the amazing people I have worked with.

There is often a sense from my clients that there is a threat somewhere, a fear of the future being fair or that anyone would be looking out to catch them should the worst happen. This means they have to fall back on all their own resources and protect those resources just in case.

Positively addressing hoarding

A pragmatic and practical look at assisting householders where their home has become dangerously full.

A workbook that focuses on where the stockpiling of items has started to majorly compromise the basic functions of the home.



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We can all understand the hormones we have that have been useful since the dawn of humankind for fight or flight but some find ourselves sitting in their homes surrounding themselves with a shield of stuff that is not defending them from a sabre toothed tiger or an invader with a spear but potentially crushing them slowly to injury or death.

A person may have been experiencing these tendencies to hoard for an average of 15 years by the time Change Your Space is invited in. Unchecked, unmitigated and exacerbated by circumstances the person can have filled their home so much that they have sacrificed all their basic comforts such as sleeping in their own bed, access to heating, space to cook, safe use of the bathroom, and ability to move about comfortably in their home.

Instead, around the home is often a mix of untouched new purchases and recycling that should have been put out for processing a long time ago. Comfort and safety has been seriously compromised by a powerful urge to hold onto, and bring close, any resources at their disposal.

The scale of the challenge

An estimated 2% of Britons face day to day life with a compulsion to hoard, that is over 1 million people. In the area covered by Change Your Space in the South West of England that is about 35,000 people. Hoarding is estimated to be twice as common as OCD, and four times as common as bipolar and schizophrenic disorders.



Chronic hoarding is defined as the level where items are being radically stockpiled and this is significantly restricting space and compromising basic functions in the home. There is difficulty discarding anything and strong feelings associated with items being moved. Only 5% of those that hoard are known to support agencies. So it is a hidden issue.

In my work as a professional organiser, it is important to make the distinction here that there are many more homes that are very full, perhaps dangerously full due to a range of other issues. Poor physical health can limit the ability to manage day to day waste and recycling, and chaotic or tragic circumstances can mean that the householder has not engaged with their belongings in some time.

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What we see in a Full House

Can the basic functions be used? The question of function is key, as those that hoard can fill up lots of spaces before it becomes really identified as an issue. Once the kitchen surfaces are so full it is not safe to cook, or the person cannot safely get into their bed and so a person sleeps on the floor or on a chair instead then that is when belongings have taken over priority to the persons wellbeing.

We can feel as if we know what a full home would look like as TV programmes and documentaries have opened up some of these closed doors for millions of viewers. This is a mixed blessing. It means that the experience of hoarding is starting to be "normalised" in that people are more aware that there are others that suffer in the same way, but also has the negative effect of imagining that some of these extreme cases are completely type, when in reality everyone is different and how they manage their homes to what ends is different.

In homes that are dangerously full we can see physical trip hazards, fire hazards, exits are blocked, and risks of vermin. Stockpiled items that are preventing doors from being opened or closed, and which make throughways extremely narrow.

In the winter we have the most calls as the boiler may fail but the tradespeople cannot access the radiators, the water tank or the boiler to resolve the problem. Many households cannot use their central heating system at all or efficiently, and fire officers will tell you the clear risks of temporary free standing heaters in homes with lots of available "fuel".

There will be those for whom their full home is symptomatic of a deep psychological trauma, and perhaps an ingrained disorder that will require specific psychiatric support.

There will be others who with careful support can review their belongings and start to sustain progress themselves and bring back function themselves. I suppose what I am saying is that the stated 2% may be only that extremely serious end, and that we may have many more people whose homes have become dangerously full but may not meet all that criteria for a hoarding disorder.

We are all on a spectrum. 1 in 3 of us is estimated to have enough clutter (items that we no longer require) to fill a whole room, and estimated 30% of our homes is taken up with belongings we have no attachment or use for.

Crucially though, this workbook focuses on the homes where the stockpiling of items has started to majorly compromise the basic functions of the home.

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Undetected and unresolved damp or the sheer weight of belongings can cause structural problems. I have seen ceilings that have bowed under the strain. I have seen windows that are falling out but you were unable to see them clearly from inside.

I am always looking around in the initial visit to see what in their home may be out to cause them harm. I am not just looking at volume density, but also what is where and the opportunities and risks.

What the householder reports

We conducted an open morning for National Hoarding Awareness Week in 2014 with the Devon and Somerset Fire and Rescue Service. Those that attended spent about 90 minutes explaining in detail why their home was full, but then froze at the prospect of a visit. It is commonly my experience that clients have detailed stories and explanations around why their homes are full.

There can be a script at the heart of it all, whether it is a waiting for renovations or a move to have more storage, or a compulsion to shop without knowing what they already own, there may be a routine such as going out twice a week and buying items they know they have no use for but it has become habit.

I met a gentleman who went out twice a week into town and used to buy two or three DIY items while he was out and bring them back. The issue was that he was in his eighties and no longer able to do any DIY due to poor eyesight and in his one bedroomed flat he was stockpiling unopened boxes of drills and other heavy duty items. My first instinct in supporting him and the family was that it is great he is going out twice a week and that also DIY must be an important part of his identity. There would be little point suggesting he simply stop altogether, as it was a habit mixed in with positive behaviours, including the walk to the bus station. We discussed the possibility of him purchasing smaller items such as small screwdrivers and nails, nothing any larger than an envelope.

The automatic solutions that come to mind if you want a "quick fix" will not be readily accepted and I find that you have to understand what the person is saying about their situation more broadly and their sense of control or otherwise over their environment.



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There is a reported reluctance to have anyone over to visit. Social isolation is a big risk. Age UK conducted a study of 6,500 UK men and women aged over 52 found that being isolated from family and friends was linked with a 26% higher death risk over seven years. Social isolation is a killer. So it is bad news when someone has a home they feel embarrassed to open up to others.

Self – neglect is a growing area where we see that hoarding is part of struggling to discard waste due to not having the will or physical strength to collate and take it out. We should not underestimate how even the ease of kerbside recycling can be daunting to some as they become anxious about that they should and should not put in. Waste can quickly accumulate.

Havard University (Hooley and Hazel, 2015) recently published a study that showed that people who hoard tend to experience increased vulnerability to stress and negative emotions (high neuroticism). They also tend to be more impulsive. The raised levels of impulsiveness may increase the likelihood that people who hoard will more readily buy or keep objects, resulting in the excessive accumulation of items. Lower levels of conscientiousness may also mean that it is easier for clutter to get out of hand. Then a diminished ability to cope with negative emotions could increase the problem, because individuals with hoarding behaviour may have a difficult time coping with any negative emotions associated with throwing items away. There is a fight going on against powerful negative emotions.

This research is key as for Change Your Space we often look at hoarding as a coping mechanism. We are meeting people who deep down have a really heightened sense of threat who are trying to make it better with their behaviour. This can have a great pay off, but may be the same behaviour (such as acquiring or failure to discard) that is also causing them other problems and anxieties.



Our clients are treated kindly and those coping mechanisms carefully reviewed. Gradual change aims to take away the worst of the negative effects their coping behaviours but not leaving them exposed to the negative feelings that behaviour seeks to defend them from.

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2.The approach by Change Your Space

Who are you and where are you going?

Change Your Space is a professional organising and decluttering service based in Devon serving the South West of England. We have supported hundreds of people in their homes at all levels and pride ourselves on an empathic approach that makes tangible improvements. We are there to encourage the client to have control over the process of sorting their belongings.

Key for us is the following:

- What is the story of the home and the persons place in it?
- What are their interests and those things that define them?
- What are the belongings that they treasure most and which are those they struggle with?
- What are their weekly habits in terms of acquisition and discarding of items?
- How is their family and friend network and what support do they offer?
- What is their motivation for change?

We will come to our practical considerations, but these are right at the centre as it is often said it is rarely about the stuff. What we mean is that we are dealing with the person, and their hopes, fears and identity. Moving their belongings around is a big deal.

We are in their home, their private space, and in their cupboards so we need to have trust but also able to pre-empt when the householders' anxiety levels are going to be heightened and about what.

It is an evolving knowledge of course, and one that cannot replicate a counselling relationship given the short amounts of face to face time and the practical task at hand. It has elements of that therapeutic relationship though.

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Change Your Space aim to carefully understand a person so that we can offer the best solutions in their home that will allow them to sustain the progress to live comfortably but also manage their everyday anxieties.

I am reminded of a scene in the 1986 film Labyrinth where the heroine is about to locate the Goblin city and the Goblin King tries to stop her in her tracks by placing her back in a room that looks just like her wonderful bedroom with all her beloved toys and belongings. She has had an ordeal getting this far and so you genuinely understand if she just cuddled up in her own bed and did not move. But then she remembers the bigger picture "What was I doing?" she asks herself, and when she realises she has an epiphany saying: "This is all just junk." She then climbs out to finish the important task of rescuing her infant brother.

We could all do with looking around at our belongings and say to ourselves "What was I actually doing before all this?" Are our belongings a distraction or are they a positive augmentation of who we are and our positive future? This is what we at Change Your Space want to know.

I once met a lady who had lost her home in the floods in Somerset in 2013 and she said to me "Oh I had been meaning to have a sort out anyway." I could not believe it. Most of us if we had a trauma of losing everything would be distraught, but she made light of it. "I am still standing" she said. She may have been saying that of course and really hurt inside, but the premise is good. We would be still standing if we had less. We would just like to be in control of its scale back, and to treasure items that speak to us as individuals.

Practical steps

Change Your Space is also a pragmatic service so once we have established a sense of the person we examine the physical aspect of the home; the belongings, the function, the storage. We are scanning using our expert knowledge in how to gains space and organisation.

We can test out options with the householder, as there are many organisation techniques but we have to find ones that will work for the individual so they can maintain it, and options that make them feel comfortable. We are again working within the parameters of gently stretching them without trying to drive them into fear.

My clients do not want anyone to come in and bulldoze through and say "Voila! Your home is transformed!". They want to be an active driving agent of that change and benefit from our support, and careful advice.

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We look out for the following:

- Are items very mixed? Or are they stockpiled like with like?
- Are belongs kept broadly in the correct places for usage (what we call 'zoning')
- How is the householder processing incoming items and items for waste and recycling?
- What storage is available and is it maximised?
- What are the day to day pressure points?
- Are there spaces that have not been reviewed for some time?

The next step would be to start work in an area that will allow a proof on concept without raising the person's anxiety levels to a point that they never want to start the process ever again. A gentle process with a clearly defined area is the best start.

What do we do?

1. Bring items out of store spaces into a processing area. We may have cleared the space just for this purpose. We are in the back of cupboards and gaining access into the spaces that have not been reviewed for a while. It is easy to underestimate the physical task of retrieving stuff from the back of cupboards. This is where we start, getting items out to be viewed.

2. Categorise and present so that the client can make decisions. In placing items out into the processing area we are looking to make life easier for them by trying to categorise items so they can be free to simply look and conduct a first sift. This first sift means simply looking for the items that do not need to be in their home. A lovely client of mine used to say "I no longer require this" as he found items that could go for charitable donation, recycling or waste. We keep it simple as for example there are cases where a client has hoarded a specific item and that specific collection can be untouched but all other items in the home reviewed to make the home safe. Start with the easy gains.

We can bring containers too so that items are more efficiently stored. Clients are often amazed what we can store away effectively for them without much actually leaving the home. In very full homes though we do need to look at what does not belong in the house, but it is also vital that items are stored and categorised in a way that brings more order to the home instantly.

3. Set up the waste, recycling and donation areas as clear as possible. It is not just the practical aspect here but of course we always try and understand as best as we can what the person's feelings are about recycling and donations. It will vary from client to client. We want to keep the options as clear and open to the person as possible, so I have my colourful boxes: green for recycling, blue bags for donation, black bags for waste and they are set up clearly around the person for ease.

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3. How sessions are structured

There are two ways in which we are contacted to work with people whose homes have become dangerously full.

Public Service referral

We have many referrals from a public agency such as the housing department of the local council, community enablers from social services, or from services such as Fire and Rescue. We structure our approach with public agencies as follows:

Initial Visit and Assessment

An initial visit is arranged by the referral agency with the householder where Change Your Space will be introduced. The householder will have given permission for our attendance and understand that (subject to feeling comfortable) this first visit will be up to three hours. We encourage referral agencies to introduce Change Your Space as:

“We have an independent team that we work with who specialise in supporting householders to manage their homes and improve their safety. They are experts in sorting and organising belongings. Would you like to meet with them without obligation to see if they may be useful in assisting you to gain control of your home?”

Change Your Space attend this visit and explain all the terms and conditions and ask all the key questions about the householder and have a tour round the home to ascertain our practical options too. We emphasise the confidentiality of the service but explain the necessity of a report to the referral agency to outline our practical progress. We also clarify that anything that is to leave the home say out to their wheelie bins, into recycling or with us for charitable donation will only cross the threshold of their home at their express verbal agreement.

We have used all sorts of bespoke ways to ensure the person enjoys the process of sorting their belongings or at least that it is not as bad as they thought it was going to be and they are still intact. That is a breakthrough.

In all aspects we are looking at the capacity and opportunities within the person's make-up to aid the process of making decisions about their belongings, and to see the gain in their home. The approach is as bespoke as the person is unique.

Handling their belongings can be a first step to desensitising the process of letting items go, flexing their decision making muscles. All of this while honouring the person and restoring their relationship to their belongings and home.

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The referral agency officer can leave after 30 minutes and if the householder is comfortable then Change Your Space then conduct a short proof of concept project with the householder. This may be clear around the sink, or the back door or by their armchair. It has to be a project the householder is comfortable with and is achievable in a couple of hours.

This provides the basis of the details Initial Engagement Report for the referral agency. This report indicates whether Change Your Space will be able to support the householder further, and if further sessions are appropriate.

In this report we will not divulge any personal information, or conversations that we have had, but report just the facts about spaces we have managed to make safer and our sense of how the client has participated and received the intervention.

We use tools such as the International OCD Clutter Rating Scale to give a common language to how full each room is and add to this what is being stockpiled and where from a safety perspective. We also include some views of what the householder will find easier in their review process and what they are likely to find more difficult.



Block of organising sessions

Change Your Space has deemed the service appropriate, the householder is willing and the funding / referral agency is also supportive, so work sessions are the next step.

Change Your Space tend to recommend a model of four further sessions to establish working habits and meet aims to reduce identified risks. These are often bi-weekly so that Change Your Space can assess whether spaces are being maintained as cleared or are filling up again, and to match the householders energy and motivation levels for any progress between sessions.

Once these sessions are completed, Change Your Space supply the referral agency with a full evaluation with before and after pictures (with the householders permission) and description of progress. It will include recommendations to maintain the progress, such as family support, social services intervention, a cleaning service or a twice a year session with Change Your Space.

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Private clients

There can be a call directly from the householder who has been prompted to address their home, maybe due to

- A life event (such as a deterioration in health)
- A positive ambition (wanting to have family over to visit, or replace their kitchen)
- Avoid a complaint (so responding to enforcement action by local Environmental Health, or to allow repairs to be conducted on their home).

The first call may be from a family member or a friend. In these cases, we always give as much information as possible about how the service works (and offer them this resource to read through), and encourage the concerned individual to speak directly to the householder. We will only speak to the householder directly and set up an initial consultation, or if there is limited capacity we will assess whether the family member (or carer) is the appropriate person to arrange the first session and have them present.

Initial telephone call

Change Your Space always appreciate that to make that first call is a significant step in what may be perceived as a deeply personal issue. We are always sensitive to this and if we know that this is a home that is dangerously full, we put aside an appropriate amount of time to speak.

The aim of the call is to offer reassurance that it is worth trying a first three-hour work session to make progress and prove concept. Terms and conditions are issued in advance and private clients pre-pay for their organising session.

Organising sessions

Private clients can either just arrange each session as it suits them or block book sessions for the year. It is vital that Change Your Space understand their aims and expectations and identify tangible projects that we can make steps to complete for them. Change Your Space have expertise in understanding how long it will take to sort a space to make it manageable, but there are a lot of unknown variables, so we are as realistic as possible. In short we tend to suggest that if a home is dangerously full, then the client will need to consider a bi-weekly session for 3 months to make real progress.

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4. Case examples

Miss P

Miss P had been living for years with hoarding as part of her other mental health issues. Her sister made contact with the service, and Miss P agreed to an initial visit after 2 weeks. An organising session was arranged but then postponed. Three months later the organising session went ahead and we started on the kitchen area as a proof of concept area as it was the bedroom that was very full.

In the second organising session, Miss P permitted for us to start work on her bedroom so that she could start to sleep in her bed rather than the sofa. We set up an arrangement of 2-hour work sessions (as she found the process demanding), where items were brought out to the lounge and clothing put into containers (and labelled), and paperwork she would sift through with a recycling box on one side and keep box on the other of where she sat.

Miss P can now access her clothing and sleep in her bed. There is still a volume of paperwork to sift through, but it has been moved back in the room and containerised so that there is floor space. Organising sessions were privately funded by a family member. We are now one year in from when we first conducted a visit. Trust has been fully established and sessions are every 6 weeks.

Mr and Mrs C

Mr and Mrs C had moved house at the request of the council and had filled the new home with belongings that had not been reviewed for many years. The client was initially sceptical, but then really participated fully with sorting through their belongings and requested two skips to dispose of unwanted furniture.

His personal collection of books that prevented him from sleeping in his own bed was not addressed in the 4 council funded organising sessions. Crucially however, the second bedroom for his mother was made safe, and throughways made accessible.

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