



The British  
Psychological Society



Division of  
Clinical Psychology



# A Psychological Perspective on Hoarding

DCP Good Practice  
Guidelines

*Edited by  
Sophie Holmes*

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*\* Not their actual names*

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Socrates when presented with a mass of things for sale in a market would say to himself:

*'How many things I have no need of.'*

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## Terms Used

We have attempted to use terms which keep the person central to our thinking and work and do not imply a particular framework of understanding. We have referred to experiences, behaviours and difficulties rather than symptoms of illness. The terms 'client' and 'service user' are both commonly used by clinical psychologists, and although both are subject to debate, they are used here on occasion. We have tried to avoid labelling people, and hence refer to people with hoarding difficulties, rather than using the terms 'hoarder' or 'patient'.

We have included descriptions of what it's like to have difficulties with hoarding from people expert through experience. Some have chosen to use their own names, and some have chosen a pseudonym (indicated with an asterisk in the list of contributors), some prefer to remain anonymous.

## Division of Clinical Psychology – Equality and Diversity Statement

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# Executive summary

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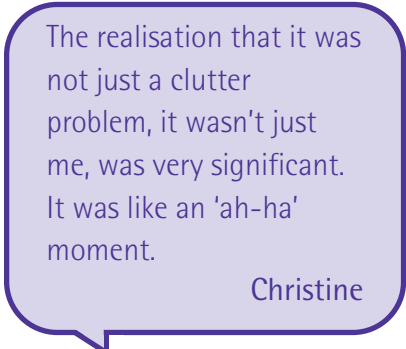
This document provides information, guidance and recommendations for people working with those with hoarding difficulties. It is intended to be read by clinical or counselling psychologists, and used as a resource by those working both within NHS, social care and/or independently. It provides information on what hoarding is, and the evidence for psychological intervention. It provides advice about management and care for those working with people with hoarding difficulties and for those commissioning services.

## What is hoarding?

Hoarding is now being recognised as a distinct mental health difficulty of its own, with specific issues affecting access to services and psychological intervention. Hoarding can have a huge impact on a person's ability to function independently and can carry a high level of risk for themselves and others. It can cause high levels of distress for those sharing a home with or living close to the person who hoards, and can cause difficulties for communities working with people who hoard.

## DCP recommendations

1. Mental health and social care services should provide services for people with hoarding difficulties regardless of how they access services.
2. Everybody working with people who hoard should have access to training and information about good practice to ensure competence in the assessment of and interventions for hoarding.
3. Interventions for people who hoard need to be broader than focused on the individual. Interventions need to be offered to the wider network, thus supporting the person and the community in which they live.
4. An increase in research evidence is required to improve our understanding of interventions, and to increase the evidence base for them, including comparisons of individual therapy and family intervention, and an understanding of the adaptations required to improve engagement and effectiveness significantly.
5. New interventions need to be developed and trialled.
6. The national media should seek advice from experts including clinical psychologists about the portrayal of people with hoarding problems and desist from using mental health problems to entertain and shock the public.



The realisation that it was not just a clutter problem, it wasn't just me, was very significant. It was like an 'ah-ha' moment.

Christine

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## PART 1:

# What is hoarding and how do we recognise it?

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### Key points

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- Hoarding difficulties are a combination of excessive acquisition of items, build-up of clutter and problems with disposal.
- With a specific definition and identifiable characteristics, hoarding is recognised as an entity in its own right.
- Hoarding difficulties have a relatively high prevalence in comparison with more familiar problems in which services intervene.

Hoarding is now recognised as a distinct mental health difficulty on its own rather than solely an aspect of obsessional compulsive difficulties or as a 'lifestyle choice'. Steketee et al. (2000) have developed and used a definition for many years but only now is hoarding included in DSM-5 as a discrete and separate disorder (APA, 2013). While there are debates about the usefulness of diagnosis (BPS, 2011), an acknowledgement of the very real and distinct difficulties associated with hoarding has been widely valued.

There are some very specific issues relevant for working with people who hoard that differ from other mental health problems. An acknowledgement of hoarding as a mental health problem allows for greater research evidence to develop, and an improved understanding of how we best help those struggling with it and those affected by it. In addition, many people with hoarding difficulties have been very gratified to see it recognised 'officially'.

### A definition of hoarding

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A widely accepted definition of hoarding developed by Steketee et al. (2000) includes a person having difficulties with:

1. Compulsive acquisition of objects, with marked and gross associated difficulties with discard, creating avoidance of discard behaviour.
2. Living spaces becoming so full of objects (*i.e. excessively cluttered*) that the use of rooms becomes circumscribed or very *restricted*. For example, the person may be unable to use the bathroom, or sleep in their own bed because of the accumulation of belongings/possessions.
3. Significant associated *distress* and/or *functional impairment*. The key thing here is it does not have to be both. People can struggle with hoarding with extreme functional impairment, without apparent significant distress. For such people, the hoarding is described as *ego syntonic*.

I like to see it mount up sometimes ... because I think I can find another use for it.

Danielle



# People and possessions

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Hoarding is a behaviour that is not confined to humans. No other species, however, comes close to human beings in how we mediate our lives through objects. In understanding hoarding it is useful to keep this in mind and not disconnect the unusual interactions people have with objects generally from the behaviour of people with hoarding difficulties.

People develop attachments (and even intimacy) with inanimate objects:

*We become attached to objects out of sentiment, perhaps, or for their symbolic value – a wedding ring, a grandmother's quilt, an old fountain pen – all of which may commemorate personal history. We seem to accept the idea that things have a life of their own. And that acceptance is the beginning of having an emotional relationship with inanimate objects ... we seem to have developed a psychic intimacy with stuff.*

(Busch, 2004, pp.15-16).

The concept of possession of objects as if *part of ourselves* is established by the age of two. In childhood, intense relationships can develop with one particular object to which the obvious term *attachment object* is ascribed. The term *transitional object* is also used as the object is seen to provide a role in gaining independence from parents. In the teenage years, possessions start to act as a crutch for the self (Jarrett, 2013). For instance, when children in the age range 8-18 years were asked 'What makes you happy?', they chose a material possession – a tendency which peaked in middle adolescence (Chaplin & John, 2007). At this time, possessions can increasingly become a reflection of who or what we are, and this continues into adulthood. Thus, our relationship with objects over our lifespan has a developmental progression.

Excessive acquisition of possessions (and often conspicuous consumption) as a marker of social status has been increasingly encouraged by the mass media since the 1950s. Objects collected may also convey messages about membership of a particular group.

*Like a uniform, our possessions of specific objects and brands can also signal our membership of social groups, both to others and to ourselves.*

(Jarrett, 2013)

A football fan, for example, may collect everything they can that is related to their team.

In older life, our possessions take on an increased role as *aide de memoires* of the life that has been lived, as an aid to reflection, for nostalgia and also a source of comfort. Mostly, this is healthy and fits with a fulfilling ageing process. Our relationships with objects echo the framework of our relationships with people.

*As with human relationships, the attachments to our things deepens with the passage of time. Elderly people (sic) are surrounded by possessions that have followed them through good times and bad.*

(Jarrett, 2013)

Can't have any one over syndrome – CHAOS. I wonder if part of me doesn't want to have any one over.

Harry

# Acquiring possessions – collecting or hoarding?

Despite the seemingly simple developmental progression described above, it has long been recognised that people and their possessions have a complex relationship. In fact, the behavioural tendency to acquire and then retain possessions can be seen as operating on a continuum from normal/adaptive to that of excessive/pathological (Pertusa et al., 2010). There is good evidence that collecting is a common feature of everyday life. Prevalence estimates of collecting indicate that approximately one-third of the US and UK population have been collectors at some point (Pearce, 1998) with collecting particularly common (91 per cent) in children aged 6–10 (Baker & Gentry, 1996).

There appear to be five key characteristics for collecting of tangible objects (Subkowski, 2006):

1. Behavioural search, selection and storage of possessions.
2. The collection being systematic and limited in a defined area.
3. Additional interest in the background to the collection (i.e. secondary information).
4. A marked affective component (i.e. having a 'passion' for the collection).
5. A fairly long-term behaviour.

My bikes are just my hobby.

Martin

It is possible to compare and contrast collecting with hoarding (Nordsletten & Mataix-Cols, 2012 – see Table 1). An interesting feature of collecting (like hoarding) is that it often entails building a collection of objects with relatively low economic value, with individual items being granted elevated, high personal value by the collector, due to their place and position in the collection (Pearce, 1998).

**Table 1:** Differences between people who self-identify as collectors and those who self-identify as hoarders

Hoarding	Collecting
Avoidance of discard	Discard by trading to improve collection
Widespread unstructured and excessive acquisition across object categories	Themed and structured limited acquisition in discernable category
High sense of responsibility and sentimentality	Lower sense of responsibility and sentimentality
Discard difficulties are long term	Discard difficulties fluctuate
Large physical size of the hoard	Small physical size of the collection
Disorganised and chaotic display (shame and humiliation)	Organised display (pleasure and pride)
High emotional distress	Low emotional distress
High social, occupational and relational impairment	Low social, occupational and relational impairment
No shared interest with others about the objects kept	Common shared interest with a group who also collect

For some people, who might be described by others as hoarders, their identity as a collector is very significant. Even when they are described by others as hoarders, they may not see themselves as having a problem with hoarding; their view is that they have run out of room for their collection. For some people, the acquisition of items may have initially begun as a collection, but gradually spiralled out of control.

People who collect are more likely to share their interest with others – 84 per cent of people who collect describe the sharing of their interest with others as important. Collectors tend to trade items, swap, use online market places and attend specialist fairs to acquire the 'missing' item from their collection. In contrast, people who hoard are much less likely to share their interest with others.

## Living with possessions

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Another significant difference is in the ability to organise possessions in and around the home. People who collect, organise, clean and catalogue their things. They tend to be quite methodical in looking after their belongings. People who have difficulties with hoarding are unlikely to be organised about sorting and cataloguing. Collectors tend not to overwhelm their living space with possessions and this may be associated with their ability to manage and organise their possessions better. Another distinction is that collecting tends to decrease over a lifetime, a process described as steady disengagement, whereas difficulties with hoarding tend to increase with age.

Is the clutter around me  
a reflection of the  
confusion within?

Danielle

It is not known whether there is a distinct difference in the distress associated with disposal between people who hoard and people who collect. It seems likely that both groups would find disposal difficult and emotionally distressing. Both groups are likely to share a number of similar cognitions and thinking styles and have similar beliefs about the value of their belongings. In fact, there is often no difference in the objective value of items that are in a collection or in a hoard.

## Is hoarding part of obsessive compulsive difficulties?

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Hoarding has, until relatively recently, been conceptualised as a feature associated with obsessive-compulsive disorder (OCD). However, evidence has now emerged of hoarding in the complete absence of any other aspects of OCD (Bloch et al., 2008; Samuels et al., 2008). The key differences between OCD and hoarding are presented in Table 2.

Therefore, although for the purposes of this document we recognise hoarding as a distinct entity, it should be borne in mind that hoarding may also be seen as co-occurring with OCD or related to OCD. Pertusa et al. (2008) defined similarities and differences between pure hoarding and hoarding as a dimension of OCD and these are presented in Table 3 to facilitate understanding.

**Table 2:** Key differences between OCD and hoarding (Mataix-Cols et al., 2010).

Hoarding	OCD
Cognitions about possessions do not typically trigger any compulsions to perform stereotyped rituals concerning the possession (e.g. a person who hoards would not feel the need to memorise any discarded item)	Cognitions typically trigger the compulsion to perform stereotyped rituals (e.g. the upsetting and intrusive obsessive thought about being a child sex offender triggers the compulsion to cancel the thought out via repeating a prayer continually)
Hoarding cognitions, beliefs and behaviours are experienced as ego syntonic (e.g. a hoarder would not perceive the collection and storage of objects found in a skip at all unusual)	OCD thoughts and behaviours are experienced as ego dystonic (e.g. the frequent washing associated with contamination obsessions are seen as illogical, but necessary)
Less likely to agree with others about the impact of their behaviour	Usually in agreement with others that their behaviour is causing difficulties

**Table 3:** Comparison of hoarding and OCD-related hoarding

	Hoarding	OCD- driven hoarding
Hoarding of common possessions and items	Yes	Yes
Hoarding of bizarre items (e.g. faeces and urine)	No	Yes
Why they hoard	The intrinsic (usefulness in the future) or sentimental (the feeling/memories attached) value	Range of obsessional themes
Hoarding triggered by obsessions	No	Yes
Presence of other OCD symptoms (e.g. symmetry obsessions)	No	Yes
Significant clutter in the home onset	Early 30s	Mid 20s
Ego syn/dystonic	Usually ego-syntonic	Usually ego-dystonic
Checking behaviours	Rare and mild	Frequent and severe
Obsessions related to hoarding	No	Yes
Internal (i.e. cognitive) compulsions	No	Yes
Impact on functioning	Typically moderate	Typically severe

# Co-presenting difficulties

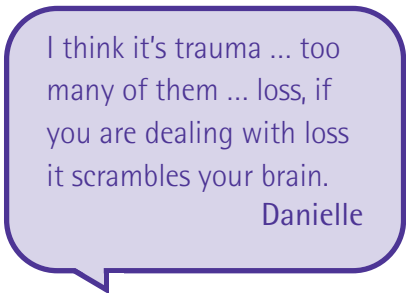
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## Depression and anxiety

Frost et al. (2011a) have identified that depression is more common among people who hoard (42.9 per cent) than among those with OCD (21.9 per cent). This potentially has a significant impact on engagement with treatment, due to problems with motivation and/or problems concentrating on tasks agreed in or between sessions. Although Frost et al. (2011a) found no increase in anxiety difficulties, they found higher rates of social anxiety among men who hoard compared with men with OCD. Steketee and Frost (2014a) report that 25 per cent of people with hoarding difficulties have social anxiety.

## Post-traumatic stress disorder (PTSD)

Overall rates of PTSD were no higher in people who hoard than in those with OCD, yet self-reported rates of trauma were higher in the hoarding group (nearly 50 per cent) (Frost et al., 2011a). Another study found that people who hoard were not only more likely to have experienced a traumatic event than those with OCD, but that the strongest association for trauma was with environmental clutter, rather than acquisition or discard difficulties (Cromer et al., 2007). Landau et al. (2011) were also able to show a higher rate of self-reported traumatic events amongst people who hoard than those with OCD, even after accounting for age, gender, education and depression.



I think it's trauma ... too many of them ... loss, if you are dealing with loss it scrambles your brain.  
Danielle

## Attention deficit/hyperactivity

There is some evidence of an association between hoarding and attention deficit/hyperactivity disorder (Hartl et al., 2005) which is likely to increase the person's difficulties with distractibility and impulsive acquisition. Frank et al. (2014) found that children with hoarding problems had higher anxiety and were more commonly diagnosed with attention deficit hyperactivity disorder (ADHD). Hacker et al. (2012) studied children with a diagnosis of ADHD and found that those who also had hoarding difficulties were more likely to show inattentive and hyperactive/impulsive symptoms.

## Hoarding and people with intellectual and developmental disabilities

Research on hoarding by people with intellectual disabilities (ID) is limited. However, some children with ID engage in hoarding that is not linked to either OCD and/or autism (Testa et al., 2011). To date, hoarding has been identified as part of the behavioural phenotype of only one specific ID syndrome, namely Prader-Willi Syndrome (PWS) (Storch et al., 2011a). The hoarding is very specifically related to the other phenotypic features of PWS and centres on hoarding food. An important finding is that such behaviour is ego dystonic, leading to significant levels of distress in people with PWS (Dykens et al., 1996). The absence of any other associations between hoarding and other specific forms of ID suggests that, other than in PWS, instances of hoarding should be regarded as idiopathic and investigated as such.



## Hoarding and autism spectrum conditions

Hoarding is particularly common in people with autism spectrum condition (ASC), both with and without intellectual disabilities, many of whom are estimated to collect material that is related to their special interest (South et al., 2005). However, the situation is complicated by the phenomenological overlap between hoarding and apparently similar behaviours associated with ASC. Similarly, this apparent overlap between ASC and hoarding has led to investigations of whether people whose primary difficulty is hoarding show more autistic traits than people with non-hoarding OCD. Such studies have identified that while people who hoard do show more autistic traits than the general population, there is no difference between people with hoarding and non-hoarding OCD (Pertusa et al., 2012). With regard to hoarding by people with ASC, the key issue is whether the behaviour is ego dystonic, as is the case in OCD, or ego syntonic, as is usually the case for the hoarding and collecting engaged in by people with ASC (Baron-Cohen, 1989). Other cases of hoarding by people with ASC may be related to issues of memory and identity: 'I collect therefore I am' (Skirrow et al., 2014).

Imagine that the physical laws under which the world operates were subject to sudden, random change ... like objects sometimes fall downward and not at other times, fire may not always be hot. How could you function in such a world? I find that other people can be as baffling as that!

Harry

## Characteristics of hoarding difficulties

### Excessive acquisition

Initially, the acquisition of objects may not itself cause difficulties, but coupled with lack of space and difficulties with discard, acquisition can lead to backlogs of possessions and significant associated impact on lifestyle. People who hoard may also experience compulsive urges to acquire things that others might consider rubbish, as well as having problems with compulsive buying. Examples might include things found in skips, rubbish bins or car boot sales.

I 'rescue' things from skips. Now I try to make it only things there are an immediate use for.

Harry



## Developing clutter

Having large amounts of possessions can creep up gradually over time. What may have started as a reasonable collection, can outgrow the space and increasingly become quite chaotic and disorganised. This can then lead to greater difficulty in knowing what is owned and where valued things are. As living space becomes increasingly compromised, organisation or sorting becomes more difficult; there simply isn't enough physical space to allow proper categorisation.

If you handle it, it's very hard not to buy it.

Danielle

## Avoiding discard

Avoidance of discard and avoidance of thinking about discard are central maintaining aspects of hoarding (Kellet et al., 2010). Throwing things away in the rubbish, recycling or giving things to others can all be difficult for people that hoard.

I struggle with tidiness... I often don't put things back where they belong after use.

Harry

## Living space

Some people who hoard are fearful of the emptiness associated with clearance. The difficulty may lie in avoidance of clear space, rather than attachment to the items themselves. Hoarding is best seen as broader than simply about objects, and may reflect concerns or dislike of space, as much as attachment to things.

I don't notice much emotional attachment to things in myself.

Harry

## Digital possessions

As we move further towards a digital world, hoarding is also being seen as associated with electronic information. People might find storage on hard drives begins to run out and buy large amounts of online storage or physical hard drives (Zerkel, 2014). This can lead to difficulties finding information, or reduce the ability of the computer to function, leading to further purchases. Difficulties associated with excessive acquisition can also apply to mobile phones – for instance, avoiding deleting apps from a smart phone can lead to the phone becoming slow and unresponsive (Ehrlich, 2012). The point at which this becomes a real problem is when the person becomes unable to use their phone, or find their photos or information due to the overwhelming amount stored or the need to keep perfect records of everything.

I find it extremely frustrating knowing I've got it but I can't find it.

Harry

## Animals

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Much less is known about animal hoarding, but just as a useful distinction can be drawn between hoarders and collectors, so a division can also be made between *animal hoarders* and *animal breeders*. The Hoarding of Animals Research Consortium (2013) gave the following criteria for identifying the hoarding of animals:

1. Having more than the typical number of companion animals.
2. Failing to provide even minimal standards of nutrition, sanitation, shelter and veterinary care.
3. Neglect often resulting in illness and death from starvation, spread of infectious disease and untreated injury/medical conditions.
4. Denial of the inability to provide this minimum care and the impact of that failure on the animals, the household and human occupants of the dwelling.
5. Persistence in accumulating and controlling animals.

In addition to issues about the welfare of the animals involved, there are also health and safety issues beyond those created by other forms of hoarding, for both the person hoarding and anyone visiting the property (Moran & Patterson, 2011).

## The difficulties associated with labelling hoarding as a mental health problem

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Hoarding is now included in DSM-5 (APA, 2013) as a discrete and separate disorder (see appendix A for further information). There are mixed views about this among colleagues and from people/families struggling with hoarding. As clinical psychologists, dealing with this tension is familiar (BPS 2013a). We use a formulation-driven approach in our work, so diagnosis is a contentious theme. Without a diagnosis, there is a risk of people being wrongly excluded from services because their difficulties are not recognised as mental health problems. For this reason, many people who struggle with hoarding have been pleased to see it included as a distinct and separate disorder. However, the definition of hoarding as a distinct disorder could potentially and wrongly imply a single cause (e.g. genes) or a single treatment (e.g. medication). While diagnosis may lead to access to mental health services, it will continue to be important that support and interventions are offered regardless of whether the person themselves identifies with the label of 'hoarder', particularly if functional impairment is high.

Difficulties with stigmatising and labelling people include the use of psychiatric descriptors such as 'insight' which are commonly found in the literature on hoarding. There is much research on the 'lack of insight' shown by people with hoarding difficulties; in one case, for instance, 21 per cent of a sample of people who hoard were described as lacking insight – significantly higher than those with OCD (Samuels et al., 2007).

A lack of insight has traditionally been ascribed to those service users who do not share the perspective of mental health

Lack of insight was more to do with total unawareness of the label ... it was total unawareness of that was what I was doing.

Anon

professionals about their problems. Tolin et al. (2010) describe the common lack of awareness of the severity of difficulties among people who hoard, with over half described as having 'poor insight' or 'delusional'. However Tolin et al's work compared the discrepancy between how the individual viewed their problem and how relatives viewed it. They found a significant difference between both parties. One of the unique aspects of hoarding as a mental health problem is the obvious visible manifestation. For most mental health difficulties, significant others would not be asked to rate their perception of their relatives' problems.

When 'lack of insight' is used to describe the person who does not see themselves as a 'hoarder', the complexity of people's understanding of their own difficulties may be missed. A person without 'insight' may still acknowledge that they have a problem. Working psychologically to understand how they see the issue may be extremely valuable and enhance therapeutic engagement. Some people with hoarding difficulties refer to their problem as 'lack of storage', while others might say it is a 'not being able to get it straight' problem. Inappropriate labelling or use of judgemental, pejorative terms risks alienating people with hoarding difficulties and may lead to disengagement with services.

Much has been written about the damaging use of language and the importance of working with people on their own identified problems while recognising their resilience. Holding this balance between acknowledgement of a very real and disabling problem while keeping the person with difficulties central to our work without further stigmatising, is essential in understanding hoarding and offering appropriate services.

## Social and cultural influences

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Hoarding needs to be considered in the wider context than as an individual difficulty. Problems arise in part due to social and material influences. The Midlands Psychology Group (2014) draw attention to the role of social inequality whether through class gender, ethnicity, sexuality or disability. Hoarding difficulties have been identified as more common amongst men, widows, the unemployed and those from less wealthy backgrounds (Samuels et al., 2008). Less is known about possible cultural differences.

The environmental context in which the person lives will determine to some extent whether they identify as having a problem hoarding. The person who lives in a large detached home will be able to amass a much larger quantity of items before their home is very cluttered, in contrast to the person who rents a small flat and is living close to other people.

The social context for the individual is likely to have a significant part to play in (1) whether the hoard is considered problematic and (2) whether statutory services become involved. Many people are simply unaware that their rights to live as they might wish in their home are not straightforward in the eye of the law.

Social isolation is a particularly key issue for people with hoarding difficulties. Both the person who hoards and their

I believe there is a spiritual element in hoarding and letting go of possessions.

Danielle

I found that it wasn't worth forming emotional attachments, as most non-family that I grew attached to went away, for one reason or another, none were my fault but I didn't know that. This was just before my hoarding really took hold.

Jim

family members can become socially isolated (Wilbram et al., 2008). People with hoarding difficulties have been reported to distance themselves both from their families and from other forms of social support, possibly in order to neutralise others' attempts to manage the clutter (Sampson et al., 2012; Tompkins, 2011; Wilbram et al., 2008).

The effect of growing older and losing social support (through bereavement) is likely to interact with the increased difficulties faced by people as they grow older. Eckfield and Wallhagen (2013) describe two aspects of this: the loss of social buffering that a partner provides and the impact of inheritance of other's belongings on the person with hoarding difficulties. In addition, changing social roles as people retire will interact and may exacerbate hoarding, as identity, social connections and increased time available to acquire all impact on hoarding.

Nobody to hold me in check.

Martin

## Why hoarding matters

It is important that people with hoarding difficulties get access to appropriate psychological interventions and advice that potentially can relieve distress or disability. Minimising or wrongly labelling hoarding can further alienate those who are in desperate situations, struggling, often in isolation, with little or no support. Recognition of the very real difficulties faced by people who hoard (and their friends, relatives and neighbours) might also mean that some of the issues affecting motivation to change and engagement with statutory services can be addressed. If the person with hoarding difficulties feels they are heard and respected without judgement, therapeutic efforts may pay dividends.

My experience, sadly, has been that help was just not available, so I long ago ceased bothering to ask for it, until now.

Harry

It is essential that those working with or supporting people with hoarding difficulties can also access services, training and advice. Identifying specific issues relevant to hoarding behaviour will increase our understanding and ability to offer appropriate interventions.



People can be both attached to and overwhelmed by their hoarding behaviour.



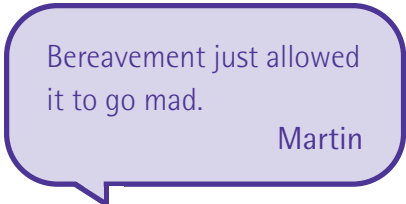
## Prevalence rates of hoarding

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Establishing prevalence of hoarding is not without its problems, as people who hoard have a tendency to minimise the problem (Tolin et al., 2010). Given also difficulties with shame and embarrassment, it would also seem likely that people with hoarding difficulties would disproportionately refuse to engage in research studies. Studies using a variety of case detection methods (Samuels et al., 2008; Iervolino et al., 2009 and Mueller et al., 2009) have estimated hoarding behaviours as prevalent in 2–6 per cent of the population. Nordsletten et al.'s (2013a) recent and well conducted, large prevalence study in the UK found a rate of 1.5 per cent.

The development of hoarding difficulties tends to start around the age of 10 to 13 years. A study of children under the age of 10 years, by Frank et al. (2014), found the onset of hoarding with OCD was at a younger age than the onset of OCD without hoarding. Perhaps unsurprisingly, the expression of hoarding among children and young people shows some differences from that seen in adults. Plimpton et al. (2009) found that children had difficulties in discarding and maintaining control over possessions, but they did not have problems with clutter or excessive acquisition. This difference is partly associated with the controls put in place by parents, which prevent acquisitions overwhelming family living space. In addition to this, children simply have had less time to accumulate items than adults (Storch et al., 2011a).

Despite the early onset of hoarding difficulties, help seeking is less common before the age of 40 (Mackin et al., 2011). People with hoarding difficulties often come to the attention of services only in later life, as a result of specific later life issues such as downsizing property, or the bereavement of a significant other who had previously helped to mitigate the impact of hoarding behaviour (Eckfield & Wallhagen, 2013).



Bereavement just allowed  
it to go mad.

Martin

Severity and impact of hoarding is likely to increase over time. Indeed, in a survey of local health departments, Frost et al. (2000) observed that over 40 per cent of hoarding complaints involved agencies for older people. The impact of hoarding in later life can be exacerbated by physical illness, cognitive decline, limited mobility and health hazards (Ayers et al., 2011; Turner et al., 2010), and Eckfield and Wallhagen (2013) reported that hoarding disproportionately affects adults over 55 years of age.

Data on the prevalence of hoarding by people with ID is limited. However, it is estimated that about 16 per cent of children with ID engage in hoarding that is not linked to either OCD and/or autism (Testa et al., 2011). Sixty per cent of people with PWS have been shown to hoard (Storch et al., 2011a).

Hoarding is particularly common in people with ASC, both with and without ID, 33 per cent of whom are estimated to collect material that is related to their special interest (South et al., 2005).

## Part 2:

# How hoarding can affect people's lives

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### Key points

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- Hoarding can put people at risk in many ways.
- Difficulties associated with hoarding can be physical and social as well as psychological.
- The effects of hoarding extend to family, friends and neighbours, and more widely to interactions with other community services.

### Physical health

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The health needs of those with severe and complex mental health problems have long been known to be worse than in the general population. People with severe hoarding difficulties are likely to be at risk of neglecting their own physical healthcare needs and have greater difficulty accessing physical health services. Increasing isolation increases the likelihood that the person may not be known to local GPs, thus creating further risk that physical health is compromised.

People with hoarding difficulties have been shown to be nearly three times more likely to be overweight or obese, and significantly more likely to report a wide range of chronic and severe medical problems (Tolin et al., 2008a), with the most common conditions including diabetes, seizures, head injury, sleep apnoea, and cardiovascular, arthritic, haematological and lung conditions (Ayers et al., 2014). The directionality and reasons for this relationship are unknown, but it is clear that many of these conditions would interfere with people's ability to manage a cluttered home environment and demonstrates the importance of assessing physical health and capability. The risks for older adults are that existing medical conditions may be exacerbated due to unsanitary housing and reduced access to health professionals (Novack, 2010).

In addition, if someone is taken seriously ill and calls for an ambulance, difficulties can arise with access. If access for the ambulance service (or fire service who may assist in certain circumstances), is compromised, there is little hope that the person lying ill could be rescued and taken to hospital. This leaves the person and potentially their family particularly vulnerable in cases of emergency.

The presence of significant numbers of rats or other pests can lead to animal urine and faeces being trapped within or under possessions. As this decays over time, ammonia will be released into the air affecting the air quality and potentially causing breathing difficulties (Reinisch, 2008).



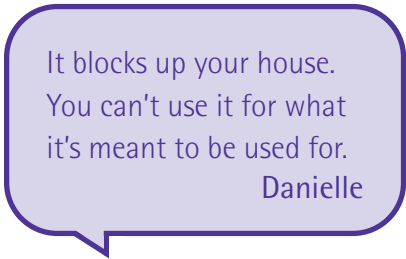
## Self-neglect

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If the person is unable to access hot water or a bathroom or simply the sink, self-care becomes increasingly unlikely and difficult. The person may find it difficult to wash clothes or keep themselves clean. This can exacerbate difficulties with isolation if the person increasingly avoids contact with other people.

Alternatively, they may engage in more acquisition behaviours, buying new clothes in the absence of any readily available clean clothes in the home. Difficulties accessing the kitchen may lead to problems with eating and drinking. This can range from people who are unable to heat any food up, or keep anything used for eating clean, or store food in unusual places where it may rapidly deteriorate, be forgotten or be eaten when well past its best.

Difficulties with organisational abilities regarding bill-paying can lead to services being removed, increasing risk that the home cannot be heated or that the phone is disconnected. The person may be aware of faults in the heating or water system, that lead to them turning off their own water supply in an attempt to prevent further problems. If this becomes a long-standing solution, the person can end up living without essential services and support.



It blocks up your house.  
You can't use it for what  
it's meant to be used for.  
Danielle

## Families

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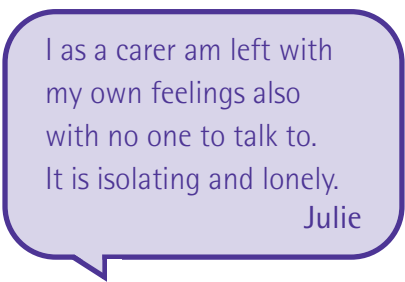
Buscher et al. (2013) summarise the effects of hoarding on families under three themes:

- quality of life
- shattered families
- rallying around.

The theme 'quality of life' describes the well-being of relatives, whereas 'shattered families' includes the impact of hoarding on family relationships and the loss of 'normal' family lives.

The theme 'rallying around' describes various responses that families have to the hoarding, both positive and negative.

For example, families are typically eager to help, but can get drawn into colluding with the hoarding as a response strategy.



I as a carer am left with  
my own feelings also  
with no one to talk to.  
It is isolating and lonely.  
Julie

Families of those who compulsively hoard may experience embarrassment, shame and worry linked to the hoarding, and may struggle with compulsive hoarding behaviours or urges of their own (Sampson, 2013). It may be that only one member of the family actually wants change, and will have to work with other relatives continuing to acquire items, while they are trying to reduce this behaviour.

Relatives make comparisons between the past and the present environmental situation, as well as detailing the current level of clutter in the house, in order to illustrate the impact hoarding has on 'normalcy' (Wilbram et al., 2008). They can feel a sense of loss as 'normal' family life and family norms and values, such as eating together at a table, inviting friends to visit or decorating the house for Christmas, are eroded. These are just some of the family rituals and traditions which may be lost in households where someone has hoarding difficulties. Adult children of hoarders have expressed this as the loss of the safe environment that once was their childhood home (Sampson, 2013).

The care of children and young people in the home of someone who hoards can be severely compromised. It may cause them embarrassment and they may be unwilling to bring friends home. It may be difficult for them to do homework, or keep their school work organised due to limited surfaces or table space available. In more extreme cases, it may prove difficult for them to sleep in their own bed or bedroom. Their clothes may be kept in a separate area of the house. There may be no floor space in which to play with toys. It may become so difficult for the parent to function that the child is not able to eat ordinary food, and may not be able to wash or have clean clothes. In more extreme situations, children may need to be cared for away from their home and parent(s). The number of people with hoarding difficulties who have had a child removed due to their difficulty in resolving the impact on their living environment is estimated to be up to three per cent (Tolin et al., 2008a).



Family relationships can be put under strain by hoarding behaviour.

Drury et al. (2014) found a significantly greater carer burden for relatives of people who hoard compared with relatives of collectors. Family members of people with hoarding problems also report higher levels of rejecting attitudes toward their relative, than seen in families where one person has OCD (Tolin et al., 2008b). The level of squalor reported by relatives was a significant predictor of carer burden and functional impairment for family members. Similarly, the rejecting attitudes reported by relatives were found to be predicted by the severity of the hoarding (Tolin et al., 2008b).

Co-habiting with a person who hoards was found to be a significant predictor of carer burden and functional impairment (Drury et al., 2014). Nordsletten et al. (2014) found that blood relatives (e.g. parents, children) of people who hoard reported higher burden scores than spouses. Despite this, spouses have reported higher distress scores than children of compulsive hoarders (Frost et al., 2011b).

My wife would say: I'm going to throw it all out! No! No! No! I need it.

Anon

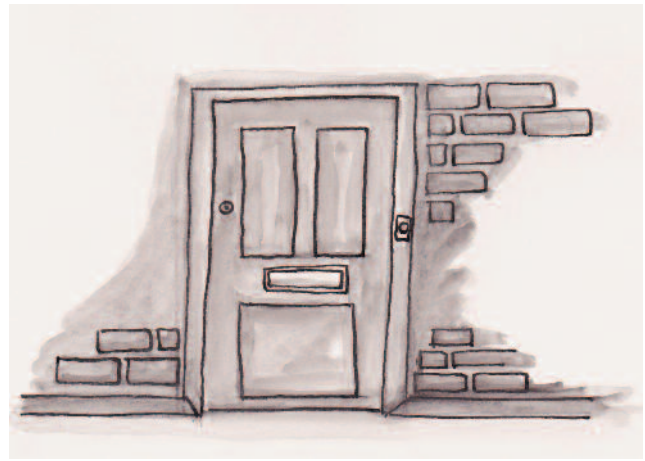
## Housing

Hoarding behaviour that compromises the ability of gas/electric services to be inspected or maintained leads to higher risk of faults developing, house fires starting and/or dangerous gas leaks.

I want this room back, and I want a room upstairs.

Danielle

Many housing associations require *reasonable* access to property and may not be able to enter the home of someone who hoards; if utility services are not able to be maintained, the risk increases that landlords will evict tenants. Tolin et al. (2008a) found that 8-12 per cent of people who hoard have been threatened with or experienced eviction. Losing post in the morass of objects can increase the risk of eviction, because the person may not necessarily be aware that the process has been initiated. Housing providers face the difficult task of working with people who may be unknown to mental health care services, and may receive little or no specialist psychological consultation or supervision in their work.



Hoarding is located in the home and can be a hidden problem.

There are many people with ID and/or ASC or complex, severe mental health difficulties, or older adults who live in supported tenancies, residential homes or nursing homes. This can lead to additional difficulties, as hoarding may well affect the lives of both co-residents and staff working in the homes. Disagreements between staff groups involved in providing care can arise, with staff from one service experiencing pressure from staff in other services to clear the room of belongings, despite the person themselves showing no wish or interest in doing this work. The clash in values from different providers of services can exacerbate general tensions. Some providers may be more willing to 'do to' clients, whereas others may see their role as supporting the client to exercise choice or take personal responsibility.

## Accidents and fire

Hoarding leaves a person (and their relatives) at high risk of accidents. Piles of belongings can become unstable and slide or fall. This can lead to people being trapped or seriously injured. Piles of objects can put strain on the physical structure of the property with disastrous results. Ceilings can collapse as a result of the weight of stored possessions, doorways can be damaged and walls weakened.

The risks of this are borne out by Australian research data which showed that although less than 0.25 per cent of house fires were of people with hoarding difficulties, 24 per cent of fire-related deaths were of people who hoard (Steketee & Frost, 2014a). The risks for older adults are even greater. As mobility and balance decreases, what once may have been manageable living conditions can become increasingly dangerous (Novack 2010).





## Financial costs

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If people are living with a huge amount of possessions, they may not be able to access their financial paperwork. They may not be working, but also may not be claiming benefits to which they are entitled. This increases the risk of them living in poverty and becoming more marginalised from society.

Maintaining attendance at work appears to be more challenging for people with hoarding difficulties than for those with other mental health problems, with Tolin et al's research (2008a) suggesting that people who hoard had an average of seven work-impairment days in a month. This places them at higher risk of losing their jobs, and thus potentially increasing their financial difficulties and isolation. In addition, losing a job may have significant impact on their sense of identity.

The costs incurred by outside agencies attempting to help or resolve the problem can quickly escalate. Mental health services may pay to have homes cleared, but may find the person becomes highly distressed at the manner in which the clearing was done and is unable to maintain change.

Environmental health departments are typically managing about four cases of hoarding per year. Of these, between one and two has no mental health services involvement (Holroyd & Price, 2009). Environmental health officers are often left trying to negotiate clearance, then using legal means to permit forced clearance. All of this entails significant cost, and while environmental health services may attempt to recoup their costs, this is often not possible and may require further lengthy legal work and additional expense.

## Part 3:

# Assessment of hoarding difficulties

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### Key points

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- Formulation requires psychosocial assessment as well as a physical assessment of the living environment.
- Assessment and action should be preceded by an agreement between the clinical psychologist and the client on the way they will work together.
- Addressing motivation difficulties must be central to improve engagement.
- Assessment tools and interview schedules can facilitate assessment.
- There are considerable benefits in involving others, such as carers and other services, in assessment, formulation and intervention.
- Cognisance of relevant legislation is required, although statutory powers should be used with caution.

In working with people referred for help with hoarding, as with any mental health problem, prior to formulation a period of psychological assessment is required. The difference with hoarding is that the assessment also requires an environmental assessment of the home and other buildings (e.g. sheds), in combination with personal history and current thoughts, feelings, behaviours and interpersonal relationships.

'Others mean well but just cannot understand your difficulties. 'Just pull yourself together,' 'Keep smiling' as a friend says to me... I am trying hard but need a hand up, not lecturing.

Harry

### Assessment

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Clinical psychologists need to consider engagement issues carefully with people who hoard, due to variations in shared understanding of the difficulties, the high degree of shame people who hoard may feel about the appearance of their home, and the likely high level of criticism they may have received from others over many years.

What helped was admitting I had a problem.

Martin

Difficulties with assessment are multiplied when the person themselves hasn't requested help. Access to appropriate services must be considered. The impact on others must be a part of assessment and be taken into consideration once decisions about appropriate services are being made. Addressing motivation will be a key part of assessment. As with any mental health issue, finding out what is causing distress, rather than pre-judging is essential. Identifying the thoughts that interfere with recognising that there is a problem and identifying subsequent behaviour change is important.

If people disengage from traditional services, it may reflect a perceived lack of usefulness of those services (BPS, 2013b). People with hoarding difficulties often present in services as a result of other people or agencies (such as housing providers) identifying a problem, rather than the person themselves. Being subject to threats of eviction or being compulsorily detained often worsen any attempts at engagement. Psychological intervention can easily appear to work to the same agenda as legal forces. Engaging in identifying and working to the priorities of the client may in fact lead to not addressing hoarding concerns at all. However, generic recovery-focused work can be a valuable way of gaining credibility of having something useful to offer. This can then potentially open the door into options for psychological intervention. The tension for clinical psychologists is then between keeping in mind the client's goals and the needs of relatives and the wider community.

I wanted to get support without being judged or stigmatised.

Anon

Assessment of older people requires an understanding of the customs and 'cohort beliefs' of those born in earlier generations (e.g. Knight, 1999; Laidlaw et al., 2003). This is an important consideration both in terms of beliefs about psychiatric or psychological input, and also with regard to beliefs about hoarding itself. For example, a history of deprivation or rationing could lead to the development of core beliefs about the importance of saving and avoiding waste that increase vulnerability to hoarding.

I will be able to fix that.

Harry

Clear, documented agreements and actions need to be put in place at every step of the engagement process with the client. This will foster an atmosphere of collaborative working, rather than the impression of applying therapies unilaterally. While this working contract can be verbally agreed with the person prior to starting any work, it can usefully be written down, and typically should contain agreement on:

- what areas of the house the clinical psychologist is free to work in with the client;
- whether the clinical psychologist needs to seek approval before touching items;
- what to do with valuables that are unearthed during de-cluttering;
- safety issues in the face of precariously stored hoards; and
- what should happen to any items that it is mutually agreed will be discarded.

In order to assess the person's situation and needs effectively, a blend of out-patient and home visits should be considered. Out-patient appointments may be necessary to complete clinical assessments (without the distraction or uncomfortableness of the home environment) and domiciliary visits are vital to assess the level at which the rooms in the home function. Without visiting the home environment, it can be difficult to get an accurate assessment of the extent of the problem. If the person is reluctant for workers to visit their home then issues of shame should be addressed, rather than minimised.

I let very few people into my home; it is always an issue if I let people visit.

Anon

## Measures

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The Clutter Image Rating Scale (CIRS) (Frost et al., 2008) assists in measuring the degree of clutter in the home. The CIRS has been psychometrically validated and is simple to use – unless levels of clutter are so high in the home that it is difficult physically to stand back from the hoard.

The CIRS requires the assessor to match the bedroom, kitchen and living room in the home to a pictorial scale of increasing levels of clutter from 1 (clear) to 9 (completely unusable). In terms of assessing and having a shared understanding of the problem, it is also useful to co-rate rooms using the CIRS with a person who hoards to 'see if they see what you see'.

The Structured Interview for Hoarding Disorder (SIHD) (Nordsletten et al., 2013b) can be used to establish and distinguish between pathological collecting, OCD or other difficulties. It is recommended as part of a full psychological assessment but will give an absence or presence rating rather than a measure of severity.

For people with difficulties with self-reporting, assessment may need to rely on both third-party assessments and behavioural products. There are no specific hoarding assessments for people with cognitive impairments, but formal measures such as the Child Saving Inventory (Storch et al., 2011b) may be useful. In the specific case of hoarding associated with PWS, Clarke et al. (2002) developed the Prader-Willi Structured Interview Questionnaire that examines both ritualistic and OCD-type behaviours, which may have clinical utility in developing case formulations with people with PWS.

An assessment of what is being hoarded may be required, which can involve counting the amount of, for example, shoes, food, pens or bodily waste that a person has accumulated. In some instances, the hoarded materials may be hidden and in other cases, possibly more often seen in ASC, the person may restrict access to the hoarded items. In the case of the latter, the person may need to be assured that the items will not be immediately removed and thrown away.

## A hoarding assessment schedule

This assessment schedule is in two parts:

- \* The first part is for the initial assessment to ascertain motivation for change
- \* The second part is for assessing the hoarding behaviour in greater detail should the person want to work on their hoarding.

Making a change to a person's living environment can be a profound thing to do. The clinician needs to remember this at all times, particularly during the initial assessment. It is easy to jump to conclusions that because it is so obvious to you, you and the client agree on what exactly the problem is. In the first assessment session, bear in mind the cycle of change and where the client may be on it. Do not assume that they want change. If the client does want change then there is a follow-up interview which is focused on addressing the hoarding.

### Part One: Questions for initial assessment and motivation for change

- 1) What do you see as the problem, if there is a problem at all?
- 2) What is causing you distress at the moment?
- 3) What are your priorities for change?
- 4) Is your living environment, your home, causing you distress or are you happy with it?
- 5) Have people said to you that your living environment needs to change?
- 6) If your living environment changed, how would this affect you?
- 7) If your living environment were different, what could you then do?
- 8) If your living environment were different, what could you no longer do?
- 9) Do you consider your living environment to be how you would want it to be?
- 10) Do you think that you have a problem with any or all of the following:
  - i) Buying things that you do not need?
  - ii) Organising the things that you have?
  - iii) Keeping your things clean?
  - iv) Getting rid of things?
- 11) Do you consider that you just need more storage?
- 12) Do you consider that throwing things away is wasteful?
- 13) Do you think that throwing things away would be harmful to the environment?
- 14) Do you keep things because they might come in useful one day?

## Part Two: Questions for assessing hoarding behaviours

If the client is interested in addressing their hoarding behaviour, the following questions can be asked either at the same session or at the next. Sometimes it might be productive to let them have time to reflect and to ask these questions at a second session. Sometimes it will be best to seize the day and ask them at the first appointment. Clinical judgement will determine which approach to follow. Use the CIRS as part of the assessment.

- 1) Please can we have a look at each room in your house and tell me what you do and do not like about them and what you would like to change?
- 2) Can you tell me what things are most important to you in your home? For example, if you were told that you had 30 minutes to evacuate the property, what would you take with you?
- 3) What are the objects and items in your house that would be easiest for you to get rid of?
- 4) Tell me about how you acquire things: what do you buy, where and when? What are you given?
- 5) How do you organise your things: do you have strategies and plans for how you do this? If not, would you like to develop some?
- 6) What is your current routine for cleaning your home? Would you like to change it at all?
- 7) How do you get rid of things from your home? Do you:
  - i) Bin things that you do not need at regular intervals?
  - ii) Put things in the charity bin or give things to charity shops?
  - iii) Give things to friends?
  - iv) Take things to car boot sales?
- 8) What areas of the house would we be free to work in?
- 9) Do I have permission to touch things?
- 10) What will we do if we find valuables unearthed during the de-cluttering?
- 11) What shall we agree about the safety of working in some rooms if they are very cluttered – what is our agreement to keep safe?
- 12) What is our agreement about discarding items and what happens to them when they are gone?

Developed by Whomsley and Holmes



## Involving others: carers and other services

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Working with people affected by hoarding behaviour can be just as effective as working with the individual themselves. A focus which is solely individualistic will miss the complexity of the difficulties associated with hoarding.

A first step may be to identify who is involved. For example, housing support workers may not even be aware of the involvement of mental health services. It is not unheard of for a person to have several different agencies supporting them, all of which are unaware of each other.

The motivation to change of the person who hoards can be enhanced by involving others affected by the hoarding behaviour. It would seem essential to identify the effects on others as part of a thorough assessment, even if the person themselves views things differently. The views of those sharing the home or visiting can be helpful in addressing reasons to make changes.

The assessment can be informed by clarifying the goals of those affected in behavioural terms. Being specific and focused can increase the chance that change can happen. Facilitating discussions between all concerned can help move vague comments, such as 'it needs to be cleared', to more focused comments based on practical considerations, such as 'the plumber needs access to the radiators' or 'the bin bags in the front garden need to be moved'.

When working with networks, clinical psychologists can mistakenly assume everyone holds the same values and thinks alike. In practice, organisations differ; even teams within the same service can hold conflicting views on the ability of people to clear their homes. Carers and external agencies can benefit from support in identifying priorities and areas that are essential to clear versus things that can be left, or worked on in the future. Clinical psychologists may be able to facilitate the clarification of expectations and understanding, and set clear, achievable behavioural goals for change.

In summary, therefore, the assessment of hoarding requires an integrated environmental assessment and also a traditional biopsychosocial assessment in order to attain an holistic picture of the person's difficulties; clinical psychologists need to accept that assessment may take some time.

I want to get it sorted so  
I don't leave my children  
with the muddle.

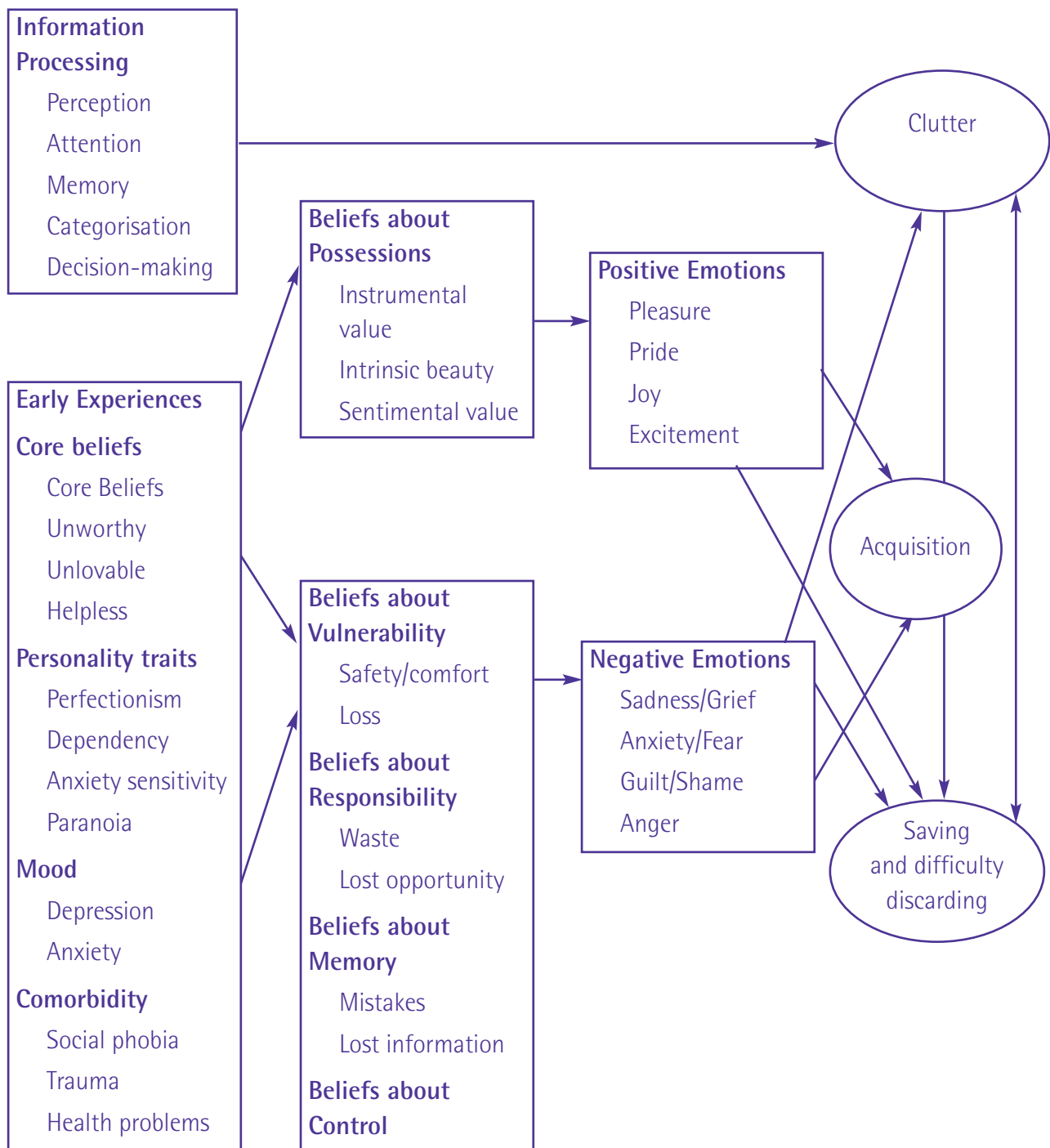
Danielle

I've had pressure from  
others, my friends and  
family would be on at  
me... why do you do it?  
...the state of the house...

Anon

# Formulation

The most researched model of hoarding comes from a cognitive-behavioural understanding of distress. A cognitive behavioural (CB) model of hoarding developed by Steketee and Frost (2014a) is reproduced in Figure 1.



**Figure 1:** A cognitive behavioural model of hoarding (Steketee & Frost (2014a, 2007), reproduced with the permission of Oxford University Press, USA).

Predisposing factors might include information-processing difficulties and personality traits (e.g. perfectionism or anxiety sensitivity), and early experiences which may increase a likelihood of problems developing include the development of core beliefs such as 'I'm unworthy' or 'I'm unlovable'.

Positive beliefs about the value of possessions will lead to positive emotions such as pride/excitement, whereas negative beliefs about responsibility or memory can lead to negative emotions such as sadness, anger or fear. These are perpetuated by behaviours such as acquiring more things and/or avoidance of discard and disposal. Steketee and Frost (2014a) propose that hoarding behaviours are reinforced either positively through positive emotional states or negatively reinforced in the short-term through avoidance of the negative emotional states associated with discard.

Too good to throw out.  
Martin

The formulation needs to pay particular attention to avoidance which may take the form of behavioural avoidance but can also include cognitive aspects of avoidance, such as deferring decision-making as a way of avoiding unpleasant emotions.

A good formulation will demonstrate 'vicious cycles' of thoughts, feelings and behaviour and make the focus of intervention easily apparent to both therapist and client. The formulation model in Figure 1 has been criticised by some for the lack of attention paid to the perpetuating cycles commonly used in and familiar to most UK practitioners of CBT. Bream (2013) and colleagues at the Centre for Anxiety Disorders and Trauma at the Maudsley Hospital, London, have developed the 'vicious shamrock' model (see Figure 2) to overcome this. In the vicious shamrock, the clutter has a central role. Three main sets of beliefs are included: beliefs about acquiring, discarding and 'stuckness'. Each of these beliefs has its own set of maintaining factors, and all beliefs reinforce and in turn are maintained by the presence of the clutter. All the components of the Steketee and Frost model are included.

I'm hooked on these newspapers.  
Danielle

The vicious shamrock (Figure 2) is a work in progress; clinicians are encouraged to work creatively with it and emphasise whichever elements of the model are most useful to the client (rather than insist on filling all the boxes). A formal evaluation of the model is planned.

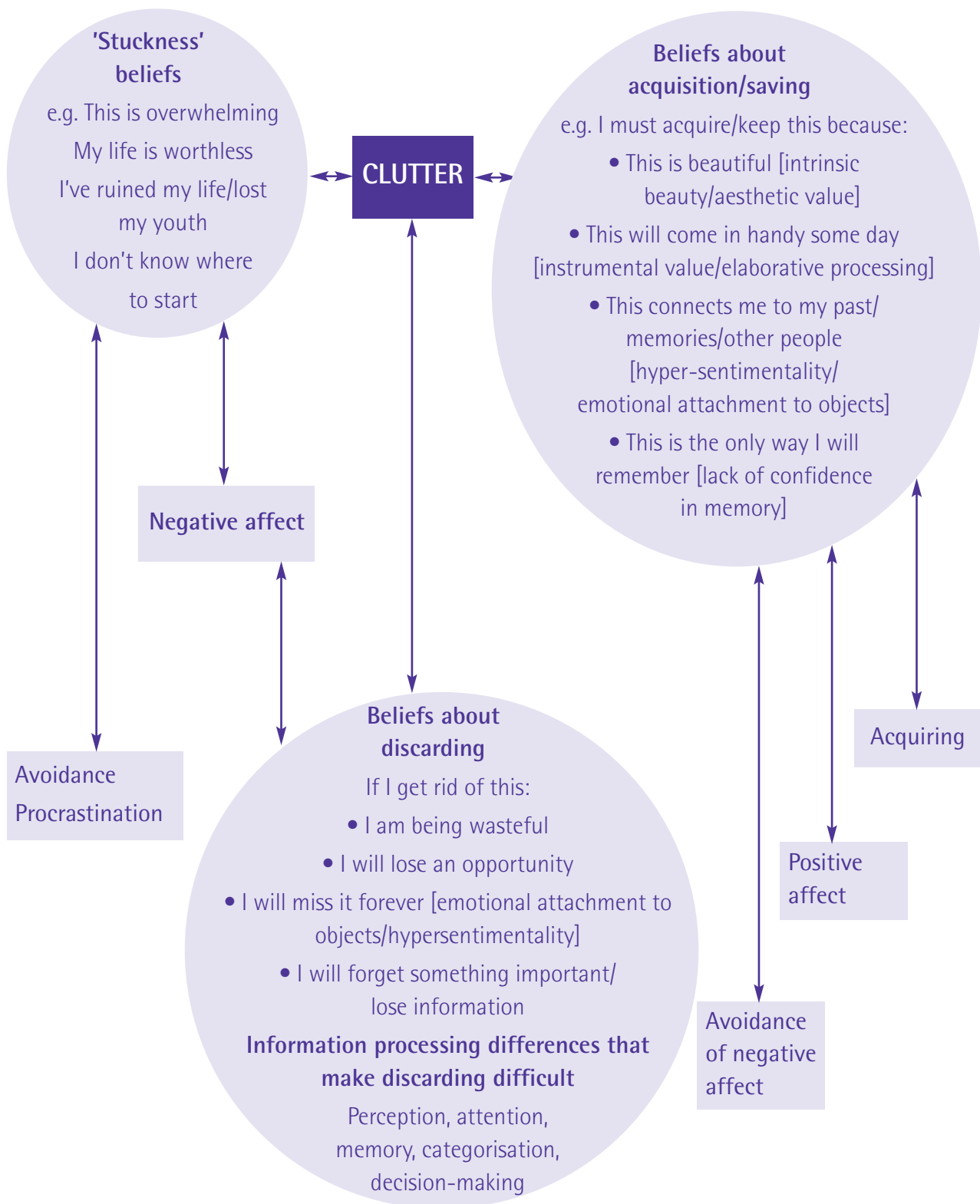
## Cognitions

The CB model suggests the importance of thoughts in perpetuating or maintaining the problem. The thoughts can be many and varied, but are not always easily accessible to the person. Unlike in OCD where thoughts are characterised as intrusive and distressing, the thoughts experienced by the person who hoards may not be upsetting or anxiety provoking, but can appear reasonable and appropriate. Examples might include 'I just need more storage space' or 'throwing things away is bad for the environment'. Other thoughts such as 'if I throw it away I might regret it', or 'I need to organise it perfectly or not bother at all' may be more open to debate. Identifying negative automatic thoughts will allow exploration of alternatives, or costs and benefits of thinking this way.

Somebody will want it.  
Martin

Family photographs – it's about ancestral line and where you come from.  
Harry

<b>Critical incidents</b> E.g. Loss, trauma, onset of depression	<b>Co-morbidity</b> E.g. Depression, social anxiety, GAD, PTSD	<b>Vulnerability factors</b> Early experiences Core beliefs: unworthy, unloveable, helpless Personality traits: perfectionism, dependency, anxiety sensitivity, paranoid
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**Figure 2: The vicious shamrock model (Bream, 2013).**

Strong attachment to items interferes with the ability to discard. People may be very attached to possessions that have personal meaning, giving them particular value. Kellett et al. (2010) identified three main types of value:

- **intrinsic value** – something that is of itself valuable, e.g. foreign currency;
- **instrumental value** – the value in being able to make future use of an item, e.g. old clothes that could be used to repair other clothes, items that can be recycled; and
- **sentimental value** – the affect associated with a possessions, e.g. old photos, diaries, or albums, as they signify or represent parts of the self, that may act as reminders of a person's life, or relationships with others.

I am appalled by the sight of neighbours' rubbish bins overflowing with refuse. Where is this 'away' that we discard to? Mars?

Harry

A strong desire not to damage the environment further may contribute to difficulties with disposal. Many people with hoarding problems have high commitment to repairing, re-using and recycling things. In some cases, value may be less strongly attached to the items themselves, but more strongly attached to places that are used for landfill.

It may be that it is rigidity and lack of flexibility in adhering to beliefs that maintains the problem. Steketee and Frost (2014a) noted that many of the thoughts expressed can be held by all, but most people can weigh up whether it's useful to continue thinking you could sell an item, if you have never in the past 20 years actually done so. Hartl et al. (2004) identified a greater tendency amongst people who hoard to report a more catastrophic misinterpretation of the results of forgetting.

If I throw this away – journals, diaries – I won't remember things like what I was actually doing at that stage of my life.

Christine

In addition they found a lower self-reported confidence in their memory.

Exploration of beliefs about the importance of the need to remember or knowing information about the item can be crucial. For some people, beliefs may include the need to retain the physical object, to facilitate the act of remembering. Some people are relatively happy to dispose of things they have checked, but the checking behaviour itself can become another aspect of a general pattern of avoidance. Meta-cognitions appear, as in anxiety problems, to be key in addressing hoarding difficulties.



People may be attached to possessions that have personal meaning.



## Information-processing difficulties

Information-processing deficits play a more significant role for people with hoarding difficulties than for people with other mental health problems or matched controls (McMillan et al., 2013). Samuels et al. (2007) describe people with hoarding difficulties as having greater difficulty with indecision and with initiating or completing tasks. A study by Hartl et al. (2004) found people with hoarding difficulties recalled less information on delayed recall, and used less effective organisational strategies. McMillan et al. (2013) found people who hoard had significantly greater perseveration errors and deficits in processing information. They identified problems which would interfere with the ability to form effective strategies, problems in concept formation and impulsivity. Difficulties in sustaining attention were associated with increased severity in hoarding difficulties. McMillan et al. (2013) also found people had greater difficulty responding appropriately to feedback, that is, changing their strategy in response to ineffectiveness.

Mackin et al's (2011) study compared people with long-standing depression, some of whom also had hoarding difficulties. Despite both groups having depression they found the hoarding group had significant difficulties in categorisation and problem-solving. They also found clinically significant impairment on information processing and verbal memory, suggesting that some neuropsychological impairment is specific to people with hoarding problems.

It is likely that executive dysfunction seen among people with hoarding difficulties will impact on the ability to sort and organise possessions, increase the tendency to see each item as unique, and therefore finding it hard to group items together, or find similarities between items. However, further research is needed to identify the relationship between hoarding behaviour and neuropsychological functioning. It is not clear whether hoarding behaviour, or simply living in highly cluttered environments, leads to deficits, or whether the deficits predispose people to develop a problem with hoarding.

Some subtle neurocognitive deficits, including difficulties with categorisation, decision-making and memory have been suggested to be associated with hoarding behaviour across the life-span (e.g. Grisham et al., 2007; Grisham et al., 2010; Hartl et al., 2004; Wincze et al., 2007). Some of these neurocognitive deficits may naturally worsen with increasing age (Deary et al., 2009). There is also the possibility that cognitive impairment is indicative of a dementia process, which in itself is sometimes associated with hoarding behaviour (Hwang et al., 1998).

You doubt your ability to make decisions.

Harry

As my house is disorganised, so too is my mind.

Harry

What's difficult is my organisational skills: cooking is hard, things get all out of sync ... you have to be very strict with yourself.

Danielle

You don't want to do it because you don't want to make mistakes.

Danielle

## Behaviour

Avoidance of disposal, or anything associated with it, serves to maintain the problem with hoarding. Disposal can trigger anxiety, but successful avoidance over many years can mask the underlying fear and lead to the problem being described as 'lack of time' or 'lack of space to sort'.

Difficulties can arise from avoidance of a whole range of things in addition to disposal. The person may avoid opening post or dealing with usual household activities such as paying bills, washing clothes, returning calls or cleaning up.

People sometimes attempt sorting but begin 'churning'. This is a term used to describe moving things from one place to another. It may seem as if the person is actively engaged in sorting and disposal, but if their actions are assessed in detail, it becomes clear that the sorting or disposal is minimal. This behaviour is actually a type of avoidance.

Avoidance of seeking help is also commonly seen among people who hoard. The avoidance of contact with any other people (or specifically those that might suggest help is required) can exacerbate the difficulties in engaging in treatment.

Avoidance may take the form of complaining about the interference of external agencies, such as housing support staff or social care. Additionally, for some an excessive preoccupation with 'the reasons why' can prevent working behaviourally. As in other mental health difficulties, people can describe waiting until they feel right before tackling the difficulty, rather than working on it despite how it feels.

## Emotions

A key aspect of the CB model is to ascertain the role and function of the emotions that the person that hoards experiences around their possessions, when planning discard, at the point of discard and following discard. As described, it may be that the behaviours serve the function of avoiding negative emotional states such as anxiety. A central component is, therefore, to understand how the person who hoards might also avoid positive and negative emotions.

Grisham et al. (2005) showed people who hoard endorse significantly less anxiety, worry, stress and negative affect than those with OCD. In addition to the tendency to experience less negative emotional affect, people with hoarding difficulties tend to have difficulties forming emotional attachments with other people (Medard & Kellett, 2014). It is not entirely clear if the difficulty in forming emotional attachments precedes the

You keep them and then you can't find them.

Danielle

You keep kicking yourself about what you haven't done.

Danielle

I think it's to do with anger ... anger is the bottom line of this little lot.

Danielle

I tend to have controlling behaviour. Some of my hoarding feels as if it relates to loss of control.

Harry

development of hoarding, or if hoarding behaviour leads to an avoidance of close emotional relationships as a means of coping with shame, embarrassment and other consequences of their behaviour.

Kellett and Holden (2014) evaluated the evidence for emotional attachment to objects and its role in hoarding. Moderate quality evidence indicated that hoarders have stronger emotional attachment to objects than both clinical and non-clinical populations. Associated effect sizes were large, suggesting that emotional attachment to objects is an important construct within hoarding.

### Other models

Little has been written about hoarding from alternative theoretical perspectives. However, given the contexts in which hoarding difficulties arise will, to some extent, affect help-seeking or a problem being identified, systemic theory potentially has much to offer. The relationship the person has with others, the relationship between them and their neighbours or community, and in many cases the relationship between services and staff, need to inform formulation. Beliefs and roles may helpfully inform the maintenance of difficulties. Attachment theory, social identity theory and models of bereavement may usefully contribute to a richer understanding of hoarding difficulties.

I rarely remember feeling valued.

Harry

### Family history

There appears to be a tendency for hoarding to run in families, occurring more frequently in relatives of those with OCD and hoarding, than in just OCD. Samuels et al.'s study (2002) of 126 people with OCD showed 12 per cent of people with hoarding difficulties had a first-degree relative with hoarding difficulties, compared with 3 per cent of people with a diagnosis of OCD but not hoarding. Iervolino et al. (2009) completed a study of 5,022 twins and found 2.3 per cent of them met caseness for hoarding, with a significantly higher rate for male twins (4.1 per cent) than female twins (2.1 per cent).

My parents had hoarding tendencies ... they were born in 1914 and lived through hard times when it often wasn't possible to get a replacement. They farmed on a very limited budget and were very good at re-using things.

Harry

## A case example using a CBT approach

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Maria is a 39-year-old woman who was born in Portugal, but moved to the UK when she was 11 years old. As a child she lived with her parents until she was two and was then cared for by her grandmother when they moved to Britain with her two older sisters. She learnt English but struggled at school, leaving with few qualifications, and worked as a health-care assistant before meeting her husband whom she married aged 20. They had two children, but when she was pregnant with the youngest he left her and she has had no contact since.

Maria remembers beginning her collection of soft toys as a child, and finding it difficult to get rid of old clothes, even when she had grown out of them. Her first home with her husband was cluttered but after he left it quickly became quite overwhelming. She found it hard not to visit charity shops, initially to buy children's clothes and toys, but increasingly her purchases extended to clothes she thought they would 'grow into', household objects that 'might come in useful' and soft toys that she described as 'I can't leave them alone in the shop, they should be in a home'. She also found it hard to get rid of papers, household bills, flyers, receipts and statements.

Her health visitor expressed concern about her care of the children and after many attempts at clearing her home, social services became involved and placed them in foster care. She continues to hope that one day she will get 'on top of it' and they will come back to live with her.

Thinking of disposing of papers led to Maria feeling anxious because she worried that she would forget something important, or would not be able to keep track of bills paid. In exploring this with a downward arrow technique, it emerged that her biggest fear was that others would 'think I'm stupid'. She tried to keep all her important papers spread out so she could easily see them and remember to pay her bills. However, she had not been able to pay any bills for many months, as her home was so cluttered she was struggling to keep organised.

Maria found it difficult to spend time at home, feeling very low and overwhelmed by thoughts such as 'I am a terrible mother to allow this to happen'. She distracted herself by walking round all the charity shops every day, and bringing home more things. The soft toys led to increased feelings of pleasure and thoughts such as 'I can give this one a good home' or 'this teddy would be a lovely present for someone'. She developed a strong identity as someone who cared about others and looked after others, while at the same time finding it hard to care for herself.

When working on sorting and discarding, Maria became quite easily distracted, worrying about losing one of her soft toys, and searching for it, while in the middle of sorting household paperwork. On discovering old soft toys, she became consumed with thoughts of how the toy might have felt being lost, and was unable to part with any of them despite most being in a very poor state of repair.

Maria found it hard to prioritise areas of her home, and her children's social worker had instructed her to 'make it suitable' for children. Her clinical psychologist worked with them both to establish the minimum steps required in order that her children could visit. They began by working in the kitchen to make space to allow food to be stored in the fridge and easy access to the fridge and cooker. They developed together a list of 'rules' about where things should go while sorting. Maria was encouraged to do behavioural work in short, regular periods of time, without spending too long deciding on any one item.

After building up some trust in her clinical psychologist, she began to test out some of her beliefs about the importance of remembering, leading to some reappraisal and decatastrophising 'forgetting'. In the past, Maria had avoided talking about her feelings about losing her children by saying to anyone who asked 'It's only temporary, when I get sorted they will come back'.

## A case example using an integrative approach

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Ken is a 57-year-old man who collects old appliances for repairs, spare parts and scrap metal. He used to work as a self-employed repairer of washing machines, but the work has slowly dried up over the years. He has his front room filled with old appliances, parts and other things he has no place to store. He lives alone after his first wife died of breast cancer over 20 years ago. His home has become increasingly filled with things 'that might come in useful.'

Ken now struggles to find the objects he wants/needs in amongst his belongings. His kitchen is piled high with objects such as empty jam jars, old scaffolding poles, clothing, cardboard boxes, old biscuit tins and household paperwork. He has two bedrooms, both full and difficult to enter, but he manages to sleep in what might be thought of as a dining room between the kitchen and sitting room.

Ken grew up in care and moved from foster home to children's home to foster home, until at about age 10 he was placed in a family where he stayed until he left school and got a job. He was close to these foster parents but they died within a year of each other when Ken was in his mid-twenties.

He met his wife while working with her father, and for several years felt welcomed and involved in their family life. He described her as down to earth and practical-minded like him. They were hoping to start a family but then she became terminally ill. After her death, Ken slowly lost touch with her family, and became increasingly isolated. He began using the front room and then the bedrooms for storage, and finds it hard to say exactly when he felt 'overwhelmed' by the hoarding.

Ken knows very little about his family of birth, but believes his mother was young and unmarried when he was born. He thought about searching for her but fears rejection, and after his wife died he gave up on the idea. He spends time trying to sort and organise, but finds it difficult to decide what to keep and what to throw away. He has managed to clear the small front garden after complaints from neighbours over many years.

As he now has health problems including leg ulcers, and is in considerable pain, Ken is finding moving about his home is getting more difficult. His GP has suggested getting house clearance people in, but the thought fills him with horror.

Ken's hoarding enables him to connect to happier times, when his wife was alive, times when he had a role as a worker and a spouse. He has strong emotional attachment to both identities and still exhibits behaviours that connect him to them. He has a belief common to many people who hoard that 'this might come in useful one day'. It is a belief that reflects sensitivity to loss, sadness from the past and the anxious belief that something bad will occur in the future. There is a sense that the future contains threat and one should hold on to resources for when bad times come.

Ken's life has loss as a defining theme: he lost his foster parents, his wife and his work role. In addition, he never knew his birth mother and the fear that she might reject him led to him losing the dream of finding her and including her in his life. His wife's death meant that he lost the potential to be a parent.

His isolation means that he loses the social reinforcement and inter-connectivity that living with others brings. His social world is a fantasy one where he interacts with the ghosts of the past in his own mind, and there is no one there to shape him gently away from the excesses of his behaviour. His physical health problems further impair his ability to solve the current situation. It is only when there is a specific threat from the neighbours that he is spurred into action.

Ken's fear of 'clearance people' reflects his distress at the idea that others will come crashing in to his world and impose their will upon it, destroying the comfort that he finds in things as they are.



## Statutory powers

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There may come a time when services (or carers) consider forcibly intervening, particularly if children or other vulnerable adults are adversely affected by the behaviour of those caring for them. In working with adults who hoard, it is essential to consider the well-being, development and welfare of children (DfES, 2003). Although the children may not be known to services, the responsibility to consider their needs is everyone's (DoH 2013). It is particularly important to have joined-up working, consistently liaising with GPs, schools and social-care services. If the needs of children are being compromised, then policies and guidance for safeguarding children in need should be followed (BPS 2014a).

### Mental health legislation

Use of Mental Health Act (MHA) legislation may be considered, either for assessment or treatment. The Mental Health Act 1983 (which was substantially amended in 2007) is the law in England and Wales that allows people with a 'mental disorder' (i.e. any disability or disorder of the mind) to be admitted to hospital, detained and treated without their consent. This is either for their own health and safety, or for the protection of other people. Scotland and Northern Ireland have their own laws about compulsory treatment for mental ill health.

Whereas the 1983 MHA focused on strengthening patients' rights to seek independent reviews of their treatment, the 2007 MHA is largely focused on public protection and risk management.

### Environmental health legislation

If the person who hoards has rubbish leaking or spilling into neighbouring property, smells emanating from or rats living among their things, then environmental health departments have recourse to legal powers.

The Prevention of Damage by Pests Act 1949 can be used but only if there is visible sight of rats. Alternatively, under the Public Health Act 1936 or the Prevention of Damage by Pests Act 1949, a 'threat of disease' or 'nuisance' can be used to get a warrant to enter and can lead to compulsory clearing and/or removal from the home.

### Mental capacity legislation

The Mental Capacity Act 2005 implemented in 2007, provides a statutory framework to empower and protect vulnerable people who are not able to make their own decisions. This Act makes clear who can take decisions, in which situations, and how they should go about this. In 2006, the BPS published guidance in relation to this Act for clinical psychologists in England and Scotland.

The key principles enshrined in the Act are:

- a presumption of capacity – every adult has the right to make his/her own decisions and must be assumed to have capacity to do so unless it is proved otherwise;
- the right for individuals to be supported to make their own decisions – people must be given all appropriate help before anyone concludes that they cannot make their own decisions;
- that individuals must retain the right to make what might be seen to be an unwise decision;
- that anything done for or on behalf of people without capacity must be in their best interests; and

- that anything done for or on behalf of people without capacity should be the least restrictive of their basic rights and freedoms.

## Safeguarding adults

An adult at risk is defined by the Department of Health as:

*a person aged 18 years or over, who is or may be in need of community care services by reason of mental or other disability, age or illness; and who is or may be unable to take care of him or herself, or unable to protect him or herself against significant harm or exploitation.*

No Secrets Guidance (DoH, 2000)

In March 2011, the Law Commission recommended that the term 'vulnerable adult' was replaced by 'adult at risk' because the term vulnerable adult may wrongly imply that some of the fault for the abuse (harm) lies with the adult being abused (harmed). It is important to note that people with capacity can also be at risk.

The degree of risk is determined by a range of interconnecting factors including personal characteristics, factors associated with their situation or environment and social factors. Risk needs to be assessed in terms of how able vulnerable adults are to make and exercise their own informed choices free from duress, pressure or undue influence of any sort, and to protect themselves from abuse (harm), neglect and exploitation.

## Difficulties in bringing statutory powers to bear

The issues with using statutory powers are many, not least the fact that forcible treatment can be an extremely traumatic process for the person involved. Use of mental health legislative powers to remove a person forcibly, followed by wholesale house clearance, rarely lead to resolution of hoarding difficulties. People describe feeling violated and distraught at the loss of control, valued possessions and self-efficacy. Forcible psychological treatment is unlikely to facilitate collaboration and development of the good therapeutic relationship essential to helping people who hoard deal with their situation.

## Part 4:

# Psychological therapies and interventions

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### Key points

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- It is critical to remain non-judgemental and create a positive working alliance when dealing with people who hoard, often in the face of stuttering and slow progress.
- The most effective approach may be to work towards improving quality of life despite mental health difficulties, rather than symptom change.
- Effective interventions include individual CBT, motivational work, and group and family interventions.

### Philosophy of care

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In order to best provide therapy, care and/or on-going management, it is important to remain non-judgemental while holding on to hope that things can change. The person themselves may have been subject to repeated draconian-style treatment and/or pressure from others. Forcible house clearance may have left a person quite traumatised and unwilling to work collaboratively for understandable reasons. They may themselves think they need to sort their life out, but despite repeated attempts have not made much progress.

I think it is really important for the psychologist to be working along with the person.

Anon

This context makes the role of those in therapeutic positions even more significant if they are able to stand alongside the person they are working with or consider whether or not it is the right time for treatment. Respect for the person is paramount. The inclusion of a co-worker who can join the clinical psychologist to work with family members and offer family intervention meetings, may be an essential step. Involving support staff or assistant psychologists can also be beneficial in setting and offering exposure-type work.

Progress is typically slow and therapeutic contracts need to reflect this and be based on measurable and clearly stated goals. Holding on to respect for the person and staying non-judgemental is particularly challenging when the pace of change feels glacial and the impact of the amount of possessions is causing harm to others.

Having a goal (or lots of small goals) helped me.

Anon

It can be extremely pressurised working alongside people who are surrounded by a large number of others insisting on change. The tendency to get drawn into expert-like directing or advising can be strong, but it is essential to try to remain collaborative and focused on the wishes of the individual who has difficulties with hoarding. Tolin et al. (2012) describe the impact on the work of professional attitudes. Health-care workers surveyed described working with people who hoard as frustrating, quite a negative experience, and having a poorer working alliance with the client. This draws attention to the need to remain diligent and interpersonally flexible and responsive when

building and maintaining a good working relationship, modifying treatment when indicated, repairing ruptures to the alliance and paying particular attention to our own thoughts of hopelessness.

## The value of reflective practice

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In any area of clinical work, it is useful for the clinical psychologist to be a reflective practitioner, and as part of their reflections to be mindful of their own values and beliefs regarding help provision. This is particularly pertinent when working with people who hoard, as many of our beliefs and assumptions about how a person should live can influence assessment outcomes.

It is important to recognise the value of the possessions the person may have built up over time, while at the same time acknowledging potential risks. The process of change is more likely to set off on the right foot if the person feels understood, and their objects are treated with respect.

## Quality of life and recovery versus 'cure'

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The importance of reducing risks, such as fire, health concerns and accidents, may be the primary motivating force for change rather than *stopping* or *extinguishing* hoarding behaviours. While the person might not appreciate the need to increase discard, they may understand the risks of precariously balanced items that might topple over and hurt them or others. They may see this as an issue that is worth trying to deal with. The motivation to address safety concerns may be helped by leverage applied from other sources, such as the threat of eviction or threat of children being removed. We may need to work towards improving quality of life despite mental health difficulties and define precisely what really is manageable change. Finding out what values the person holds dear, what they want their life to look like socially, at work and for themselves and their family, may be a way of engaging them in change that does not lead to head-on conflict. Working with change that is possible and achievable, and maintaining any changes made, is just as important as thinking treatment will remove the hoarding problem.

## Individual therapy

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### Motivational work

Ambivalence about the benefits of change can sometimes be confused with lack of insight (Steketee & Frost, 2014a). It needs to be recognised that motivation depends not only on the discrepancy between how life is and how the person wants it to be, but also on having confidence that change is possible. It may be that after a long struggle to 'get on top of things', people who present as if 'lacking insight' may actually be struggling with eroded confidence and doubts about whether their attempts to organise will work. Steketee and Frost (2014a) suggest that this may lead to them reducing the discrepancy by changing their

It was necessary to make a firm decision about change, stop acquiring unnecessary possessions and declutter my mind.

Danielle

You've got to be prepared to do the work. I've tried hard to cut down on what I bring in.

Danielle

appraisal of their current situation rather than continuing (and failing) to change their behaviour.

Clinical psychologists may want to consider cycle of change concepts in relation to referrals in terms of whether the person who hoards is pre-contemplative of change, contemplative of change or ready to change their hoarding behaviours (Prochaska & DiClemente, 1983). Although the role of motivational interviewing is recognised but currently under-researched in hoarding, clinical psychologists should be able to spot and make use of any change talk exhibited by the person who hoards (Steketee & Frost, 2007).

## Cognitive behaviour therapy

Steketee and Frost have written a useful therapist guide (2014a) and workbook (2014b) that can potentially be given to the person to use themselves. The use of Socratic questioning and 'downward arrow' can be helpful to identify negative automatic thoughts and core beliefs.

One specific strategy relating to hoarding is a process by which the person simply talks about the object, rather than engaging in 'restructuring thoughts'. Steketee and Frost (2014a) demonstrate that a disposal rate similar to that achieved by those without hoarding difficulties can be encouraged if the person spends time talking about their possessions first. Therapy may also include identifying values, imaginal work, practising key skills such as sorting and decision-making, thought-listing and habituation exercises. Therapy needs to include the strengthening of problem-solving skills, reducing acquisition, and exposure tasks. It is important that clinical psychologists avoid persuasion, as this can lead to further strengthening of beliefs that disposal is unnecessary.

Adaptations to therapy for people with cognitive impairments have been described by Rossiter and Holmes (2013), and many clinical psychologists will be

I find sorting and discarding very stressful and tiring, so can only manage a limited amount at a time.

Harry

I had sessions of CBT ... I found this useful in questioning my automatic assumptions about things. Simply to ask 'is this so?' can be very powerful technique in changing my behaviour.

Anon

### Harry describes his strategy

I found the following helpful in sorting out a kitchen cupboard and the garden shed:

- Completely empty the space and pile the contents elsewhere.
- Clean it and leave to dry out.
- Return items that 'should be there' in an ordered way.
- Discard useless items **off the premises** asap.
- Return remaining items to where they belong, if possible, or box up and store them for later organising.
- Work on a discrete, limited area; end the session with as little extra 'mess' as is practical.
- **Accept** that it will be disruptive, hard work and you will take time to get used to the new system; do only as many areas as feels comfortable within a short period. I find that it is easier to do a bit, then keep it going, then do another bit, and so on.

These are habits that I've had for most of my life; changing them for better ones will be hard.



familiar with the needs of people with additional difficulties or disabilities. Intervention to attenuate the hoarding should be based on the functional assessment and aim at achieving a balance between the ego-syntonic function of the hoarding behaviour and the needs of families and carers. In some cases, this may take the form of teaching new skills, for example about exchange, money and shopping, to enable the person to obtain and use materials in a more appropriate manner. Given the ego-syntonic nature of much hoarding by people with ASC, an intervention based on controlling the collection may be the most appropriate option. This might involve setting up a system by which the person donates, for example, a pair of shoes to charity on a weekly basis before purchasing a new pair for their collection.

Staff, carers and clinical psychologists may conceptualise the work as a linear process not unlike a house renovation project. Sorting and disposal might be imagined as work that ebbs and flows but generally once the decision has been made, it progresses in a steady manner towards clearance. In reality, clearance may progress and then return to a previous state of clutter, or even worsen, before moving towards renewed attempts at clearance. Recognition of the process of behavioural change can assist in remaining empathic when the pace of change seems stuttering or very slow (Miller & Rollnick, 2013).

## Large clear-out sessions

People presenting to services have often already experienced major clear outs. This will increase their fears about therapy and reduce their motivation to make changes. Forced clearances may change the living environment temporarily but are unlikely to lead to behaviour change. Steketee and Frost (2014a) specifically warn against this strategy and stress the impact which may be traumatic for the person. If a person is already engaged in sessions with support staff attempting to clear and sort, clinical psychologist needs to be aware of the tension between working at a manageable pace for the individual while appearing to 'slow down' the work carried out by others. It can be helpful to identify rules for sorting or disposing and draw these up with the person. These can then be shared with friends or others'.



## Identity and values

The tendency to self-identify with the mental health difficulty you struggle with can hold benefits but also bring with it significant problems. The implication of passivity and lack of control in holding a diagnostic descriptor as one's identity is clear. Therefore, identification as a mother or a musician rather than a hoarder is an important shift for people to make. Kellett et al. (2010) describe the common experience of fusion between self and possessions in people who hoard and discuss the importance of 'identity shift'. Seeing the hoarding as a 'behavioural difficulty' rather than locating it as part of the self therefore increases self-efficacy and options for change.

The idea of it being helpful to see hoarding as a 'behavioural difficulty' rather than 'part of the self' rings true to me.

Harry

## Group work

Increasingly, groups are being set up around the country to work specifically with people who have hoarding difficulties. This has immediate benefits in reducing the sense of isolation and shame associated with hoarding.

We are extremely lucky that we have a group and a group that is set up in a very supportive way. How many people have that?  
Christine

## Therapy groups

Gilliam et al. (2011) describe delivering CBT in weekly 90-minute sessions over 20 weeks. The groups had 4 to 12 people attending; however, the authors report significant concerns about engagement, with a third of people dropping out. They suggest this may have been associated with a high expectation that clients complete homework tasks.

It felt a complete relief to find a support group out there – to know that I wasn't the only one.  
Anon

## Self-help groups

A growing number of self-help groups have been established around the country. One of the first to be set up was in Surrey, co-facilitated by workers in the local mental health NHS trust, a local mental health charity and a carer (Holmes et al., 2014). The group runs monthly, is well attended and regularly includes psycho-education, personal testimonies and setting of personal goals. Other groups are now running as far and wide in the UK as Edinburgh, Plymouth and London.

I have found the group beneficial as it has provided a non-confrontational place to learn and face this problem.  
Danielle

A more structured approach to self-help groups called the *Buried in Treasures Workshop* has been developed in America, with resources and a book to guide facilitators (Frost et al., 2011c; Frost et al., 2012). The structured workshops run for 13 weeks. They are facilitated by non-professionals and held in non-mental-health settings. The dropout rate has been reported to be 10 per cent for these groups which, given the engagement difficulties for this population, is very encouraging and early indications are that this approach is as effective as CBT-based groups (Tolin et al., 2014).

## Online support

There is a wealth of information available online to support work with people who hoard, the person themselves and their relatives. Making recommendations can be challenging because applications, websites and other sources of good support change rapidly or become out of date, and good governance is difficult to establish. It is worth exploring online, with the proviso of approaching some of the less effective strategies marketed as 'psychological treatment' with caution.

## Working with carers and family members

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People who respond well to treatment tend to have carer involvement, as this can increase motivation for change. The needs or hopes of relatives can be used as motivating factors, or work can be supported by involving them in practical support around clearing. It is now well established that carers have rights to services in their own right (DoH, 2014), and that living alongside someone with a severe mental health difficulty has a significant impact on the carer.

My daughters would not have friends in and things because of the way the house was, it affected life in a big way.  
Anon

One of the issues is that, while many partners and children of people who hoard will be hugely affected by living in a house that has restricted access or is not usable for usual purposes, they may not see themselves as a 'carer'. The guiding principle of reaching out to people in relationships with those who hoard must be one of reducing distress, whether they share a house or are frequent visitors (as might be the case with adult children). The question of the effectiveness of services that focus solely on the individual rather than the family or wider community needs to be carefully considered.

Storch et al. (2011a) describe specific needs in working with young people who hoard and the essential involvement of parents, to increase their agency in targeting behaviour termed as disruptive.

Steketee (1993) found that empathy and positive interactions with significant others of the person with hoarding problems were linked with the maintenance of positive progression following behavioural treatment for OCD. A belief by significant others that the person could control their OCD, as well as criticism and anger, were correlated with relapse at follow-up 6–14 months after treatment. These results suggest that families may require psycho-education in order to better understand mental health problems, and that families of those with difficulties with hoarding should be included in the treatment process and offered therapeutic support of their own. Chasson et al. (2014) have shown promising result from training offered to relatives to improve their skills as motivators. This not only enabled family members to improve their coping skills but also increased hopefulness.

## Working with other agencies

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An increased understanding of how and what to do in working with people who hoard whose behaviour is significantly impacting on family, neighbours or the wider community can only be of benefit. A joint approach among agencies may also ease the burden on all services. In some instances, this may simply mean acknowledging that everything possible has been tried, in other cases it may be essential to explain how psychological interventions cannot be 'imposed' or 'forced' on people.

Most housing support staff have little, if any, mental health experience and may view hoarding as simple but large house-

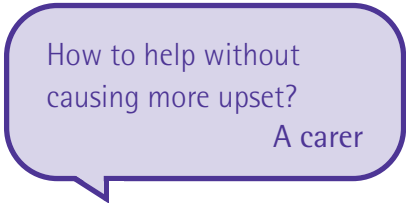
I also have a massive guilt trip when I leave the visit not having done anything in particular that has made a real difference – however small – because it feels like I have let him down and have not been much use at all.

A carer

clearance-type work. Without access to specialist help and guidance, it is likely that efforts to forcibly clear will result in the person being highly distressed and resume hoarding behaviours at the earliest opportunity (Girsham, 2011). Working in collaboration with clinical psychologists to set achievable and specific goals can enhance both the process and the effects of the work of housing support staff.

Environmental health involvement can be used as a motivator for some people. Without any other clear reasons, the pressure of external agencies can be the only thing that leads someone to ask for help. However, environmental health services frequently struggle with how to proceed with working with people who hoard.

Although in 65 per cent of environmental health work with people who hoard, mental health services are also involved (Holroyd and Price, 2009), this still leaves a large number where they are working alone or possibly with housing support services.



How to help without  
causing more upset?  
A carer

## NICE, BPS and other guidance

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There is no specific guidance for working with hoarding difficulties, but the guidelines for OCD (NICE, 2005), may be of use with those presenting with hoarding as a part of OCD. The NHS Choices website recommends CBT as the treatment of choice for hoarding (NHS, 2014). People working with those who hoard should also consider the guidance produced by their own organisations, which is likely to cover risk management, health and safety of staff and working with other agencies.

The guidance contained in this set of Good Practice Guidelines should be considered in conjunction with other relevant sets of BPS guidance, which include the following:

- DCP Good Practice Guidelines on the Use of Psychological Formulation (BPS, 2011)
- DCP Policy on Supervision (BPS, 2005)
- DCP Briefing Paper No 21: Clinical Psychologists and Assertive Outreach (BPS, 2013b)
- BPS Guidance on Assessment of Capacity (BPS, 2006)
- DCP Report on Understanding Psychosis and Schizophrenia (BPS, 2014c)
- DCP Position Statement on Classification of Behaviour and Experience in Relation to Functional Psychiatric Diagnoses – Time for a Paradigm Shift (BPS, 2013a).

## Part 5:

# Evaluation of how we are doing and future directions

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### Key points

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- Further research, both in developing existing therapeutic approaches such as CBT, and in exploring potential new approaches, is required.
- To ensure best practice, CPD, supervision and good governance are required.
- Commissioners of services need to have an understanding of the specific needs and difficulties for people with hoarding problems.

## Effective interventions: a review of the evidence

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### Individual CBT

The evaluation of CBT for hoarding difficulties includes two qualitative case studies (Cermele et al., 2001; Shafran & Tallis, 1996) and three single-case experimental designs (Hartl & Frost, 1999; Kellett, 2007; Pollock et al., 2014). The more rigorous single-case experimental studies all tend to show reduced hoarding and improved abilities to discard as a result of CBT in comparison with the baseline. Tolin et al. (2007) conducted an open trial of 26 sessions of CBT. While four out of 14 people dropped out of treatment, six out of 10 completing CBT were classed as 'treatment responders' using the SI-R. Ayers et al. (2011) applied the one-to-one CBT approach but in a sample of 12 older adult hoarders none dropped out of treatment. Results show that two of the people with hoarding difficulties actually worsened during treatment and only three could be classed as 'treatment responders' using the SI-R. The gains made by those people with hoarding problems who could make use of the CBT approach, were unfortunately not maintained at follow-up. Steketee et al. (2010) completed a wait-list control trial of individual CBT; nine people out of 46 dropped out of treatment. Improvement during CBT was statistically greater than the passive control of the wait-list across the hoarding outcome measures. A large effect size was evident and 41 per cent of completers were classed as 'treatment responders'.

### Group CBT

Four studies have tested the utility of CBT delivered in a group format. In the Steketee et al. (2000) study, six hoarders attended 15 two-hour group sessions, with statistically significant pre-post changes recorded on a modified Y-BOCS (Goodman et al., 1989). Muroff et al. (2009) delivered group CBT, with results showing modest (but statistically significant) pre-post treatment reductions. Gilliam et al. (2011) also assessed outcomes for group CBT. Significant pre-post group change was recorded, but nine of the 22 starters dropped out during treatment. Muroff et al. (2010) set out to test whether increased home-based assistance significantly improved the efficacy of group CBT. This was achieved by randomly allocating hoarders to one of three conditions: (a) 20-week group CBT (b) 20-week group CBT plus added home assistance and (c) a bibliotherapy

control condition. Both the CBT groups showed significant pre-post treatment reductions, but with no apparent differences in terms of outcome between them. While the low-intensity approach of bibliotherapy was seen to be ineffective in changing hoarding behaviour in the Muroff et al. (2010) study, Pekareva-Kochergina and Frost (2009) found significant pre-post treatment reductions following a 13-week bibliotherapy group for hoarders.

## Other therapeutic models

No outcome research has been produced that tests other psychological models of treatment – but this should be treated as absence of evidence rather than evidence of absence. There is a real need for other psychological interventions to be evaluated. The effectiveness of, for example, cognitive analytic therapy (CAT) in relation to hoarding would be useful to examine, as this more relational approach would elucidate the reciprocal roles the person experienced in relation to their possessions. Similarly, the cognitive flexibility enabled by acceptance and commitment therapy (ACT) would seem to offer the chance to accept the high sentimentality experienced regarding possessions, whilst also committing to plans for discard.

The lack of good research evidence extends to working with families. While some of the existing research around family members has been mentioned in previous sections, further studies are required, particularly those that distinguish between people with hoarding difficulties along with OCD, and people with hoarding difficulties in the absence of OCD.

If you set goals, you are setting up potential for failure.

Christine

Will I be giving away part of myself if I give this away?

Anon

## Challenges

Because hoarding is a relatively newly identified, distinct difficulty within mental health, there are many gaps in our understanding of it and the interventions that may be of use. The challenge for clinical psychologists as scientist-practitioners is to consider a range of unanswered questions, the most pressing of these major challenges being:

- What are the most acceptable forms of therapy for people who have difficulties with hoarding so as to improve engagement and reduce drop out?
- What interventions for hoarding difficulties are efficacious?
- Are outcomes maintained over time? What is the durability of psychological interventions over the long term?
- To identify the optimal means of service delivery and test whether stepped care models of intervention can be applied according to hoarding severity.
- To compare group and individual interventions within models and build the evidence base for each approach.
- To identify active ingredients of therapy and to continue to test whether home visits add value.

Someone coming into your home can feel invasive.

John



- To identify how aging interacts with hoarding outcomes.
- To identify the differences in experiences between carers who live with the person who hoards and those living away from the home.
- To identify effective interventions that involve families and carers.
- To develop a hoarding-specific therapy competency assessment tool for individual and group CBT.

## The role of the clinical psychologist

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The often very challenging nature of working with people with hoarding difficulties for clinical psychologists will be shared across housing support staff, social care staff, environmental health officers and staff from primary care (Tolin et al., 2012). All these staff require access to a psychologically informed understanding of the person who hoards, based on good research evidence and diligent psychosocial assessment. There is a potential role for shared team formulations of clients that hoard, to facilitate the development of a shared language of care and encourage coherence of the team. Clinical psychologists have a key role to play in this, and can work to increase empathy among all staff groups.

Clinical psychology competencies in staff supervision and consultation can be used to support both mental health colleagues and non-mental-health workers. Support staff can benefit from the opportunity to discuss how best to offer practical support in clearing or decluttering.

There is a clear role for clinical psychologists in offering access to psychological knowledge about the change process and specific difficulties people who hoard face, such as information-processing difficulties. Clinical psychologists are in a good position to provide training to others, both in statutory services, voluntary sector and for people who hoard and their carers.

## Research

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As scientist-practitioners, clinical psychologists are well placed to contribute to the growing evidence base about hoarding.

The research questions are broader than simply which intervention works best, and centres on the need to consider improving our theoretical understanding of hoarding. The paucity of evidence on effective interventions is nevertheless an ongoing concern. Hoarding is a serious community health problem with significant costs and risks for both the person and their family, their neighbourhood and statutory services. Research that considers the impact of intervening within the wider system as opposed to simply individually, and pays attention to the broader social and psychological consequences, would be welcome.

Who is the outcome for?  
The hoarder or the family  
member?

Anon

## Supervision

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Clinical psychologists are familiar with the benefits of regular supervision to ensure safe and appropriate practice. There is a need to ensure others working with hoarding can also access high quality supervision. In particular, staff with little or no training can benefit from case consultation and formulation to better understand the difficulties the people they are working with face.

## Continuing professional development and training

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The training needs are clear, both within clinical psychology and also for the wider networks of people involved in working to support people who hoard.

The public will benefit from improved understanding and awareness of what hoarding is and how it presents. The need to provide psychological models of mental health generally extends to and includes the importance of addressing misunderstandings about hoarding. The training needs of those in our communities who support people generally, be it GPs, social care staff, fire-fighters, workers in mental health non-statutory services and de-clutterers, need to be considered. Commissioners of services need a better understanding of the specific needs and difficulties with engagement for people with hoarding problems. Training also needs to be provided for people providing therapeutic interventions to those with mental health needs, whether in primary or secondary care services, in order to improve the outcomes of psychological interventions for this group.

The lack of awareness some professionals have on the problems and issues hoarders face and the lack of understanding of what a hoarder actually means is frustrating; the lack of empathy ... is distressing

A carer

Before the programmes. I didn't realise there was help out there. It would have helped me to have this information years ago.

Anon

It was only when the programmes were on television that I thought it's actually a mental health problem. Before that I just thought I'm creating clutter.

Anon

## Hoarding and the media

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Hoarding has held an interesting place in the media, as television programmes depicting hoarding behaviour have had a high profile. If hoarding is considered to be a distinct clinical problem, then its prevalence in programmes far outweighs the other, more common mental health conditions. Until hoarding was labelled as a mental health difficulty, it was treated as an unusual activity that some people engage in and which other people were curious about.

Hoarding can be related to people, their properties and what they keep in them, as part of a larger popular television narrative of property renovations. There are also programmes which touch on aspects of hoarding behaviour concerning the items people keep and the value that they might possess.

Media interest in hoarding is of mixed value. On the one hand,

shedding light on the issue may assist in broader understanding. On the other hand, heavily edited coverage may not give the full picture of the complexities and difficulties around hoarding behaviours (Rego, 2011).

Advice on media representation is available from the BPS Media & Ethics advisory group, and clinical psychologists are well positioned to provide a psychologically informed view of mental health. How mental health is represented in the media is in itself an area for debate with better guidelines for journalists and programme makers being much needed (Whomsley, 2013).



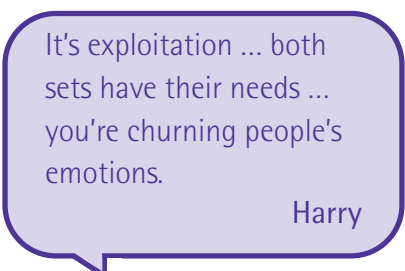
They go in and clear ...  
What happens in a few  
months' time? ... I've  
exposed myself to the  
nation.

Christine

## Governance

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In the absence of effective outcomes for people with hoarding difficulties, the risks are that through desperation, people and their families will turn to therapies and interventions which cause more distress (or no change at all) but cost financially. Without a lead from statutory services, many organisations have increased their reach to attempt to serve the needs of people who hoard. While much good work and support is provided, there is a danger of people with hoarding difficulties being exploited, as has been seen very publically on some television programmes.



It's exploitation ... both  
sets have their needs ...  
you're churning people's  
emotions.

Harry

## Service design and workforce planning

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The specific needs of people who hoard preclude the use of traditional models of mental health, whereby a person visits their GP requesting help, and is referred to a local service providing individual therapy. A more proactive style of engaging is required, involving neighbours, carers and other agencies that have concerns, which will provide a much more thorough assessment and intervention plan (see BPS 2013b for further information about engaging proactively).

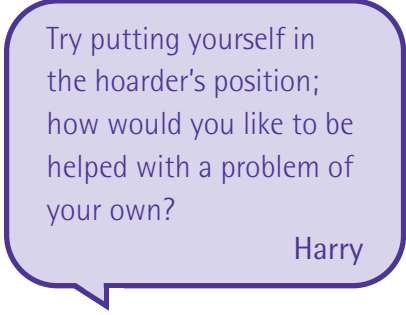
The tendency of services to work as gatekeepers and services of 'exclusion' rather than 'inclusion' may cause problems for hard-to-reach groups such as those with hoarding difficulties. It is clear that in order to reduce risks and improve quality of life, this group of people requires services that are well embedded in communities, able to reach out and respond flexibly, and visit people in their own homes.

Clinical psychologists' core competencies include psychological formulation, skills in individual therapy and the ability to implement models in a flexible, personalised and planned manner (BPS, 2014b). The importance of meta-competencies that allow adaptation of interventions to the needs of the person and being able to manage 'obstacles' to therapy has also been established (Roth & Pilling, 2007). Competencies in CBT need to be broader than simply techniques applied to a problem. Clinical psychologists need to be able to work collaboratively, sharing responsibility for

change with individuals, their families and outside agencies. Clinical psychologists need to be able to take into account different responses, concerns and ideas from family members, and engage with the psychosocial context of the person with hoarding difficulties. Respect, empathy, collaboration and attitudes that support recovery are just as fundamental as therapeutic techniques (Roth & Pilling, 2007; BPS, 2000).

Services for people who hoard need to be provided that work across the lifespan and range of severity of problems via stepped care models of service delivery. Services need to address the needs of people with multiple difficulties, including poor physical health and disabilities both physical and intellectual, and who may also be socially excluded and slow to seek help. The commissioning of education and training must also support the development of knowledge and skills required to work with people who hoard.

Clinical psychologists are well placed to draw on a range of therapeutic modalities, and intervene with families, services providing support and other organisations. Clinical psychologists are able to offer supervision, consultation, training and advice on service development, alongside evaluation and research to better inform our work (BPS, 2014b).



Try putting yourself in the hoarder's position; how would you like to be helped with a problem of your own?

Harry

## Conclusions

Hoarding has attracted increased attention from mental health professionals, the fire service, housing officers and environmental health. It is important to note that hoarding is probably more prevalent than OCD and other problems that get routine mental health service input. There is much to be learned from the existing evidence base, adapting interventions used with other difficulties, and evaluating outcomes both individually and for carers and the community. However, more research is needed to build the evidence base and develop and trial new interventions.

Clinical psychologists are well placed to take a leading role in this area, not only in delivering interventions but also in advising other staff, policy-makers and the media. Service provision needs to develop to improve engagement and reduce the impairment and distress experienced. Mental health and social care services should extend their responsibilities to provide a service for people with hoarding difficulties. It is recommended that in working with individuals with hoarding difficulties, interventions need to be behaviourally defined, realistic and achievable, or the work can be overwhelming. However, interventions need to be broader than individually focused, and should address the needs of carers, services and the wider community. Those working with people with hoarding difficulties should have access to training, to ensure they have the competencies required for their role and the interventions they are delivering.

The habit has been  
controlling us. Now we  
have to control the habit.  
Danielle

It is hoped that this set of good practice guidelines will encourage clinical psychologists across the UK to take a leading role in improving society's response to hoarding and the difficulties faced by those who hoard.



There is hope for change.

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## Resources

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- Steketee, G. & Frost, R. (2014). *Treatment for hoarding disorder therapist guide (2nd edn)*. New York: Oxford University Press.
- Help for compulsive hoarders and their families: <http://www.helpforhoarders.co.uk/>.
- Resources to assist leading the Buried in Treasures workshop:  
[http://www.ocfoundation.org/uploadedfiles/Hoarding/Help\\_for\\_Hoarding/Facilitators](http://www.ocfoundation.org/uploadedfiles/Hoarding/Help_for_Hoarding/Facilitators)
- Support for children of hoarders: <http://www.childrenofhoarders.com>.

## Appendix A: DSM-5 diagnostic criteria for hoarding disorder

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DSM-5 criteria	Descriptor
Criterion A	Persistent difficulty with discard of objects or possessions, regardless of their actual value.
Criterion B	Difficulties with discard are due to a perceived need to save the possessions and due to the distress created by discard.
Criterion C	Accumulation of clutter that congests living areas and compromises the functioning of the living area.
Criterion D	Presence of clinically significant psychological or emotional distress or impairment to social or work functioning (or any other area).
Criterion E	The hoarding is not attributable to any other medical condition.
Criterion F	The hoarding is not better accounted by the symptoms of another mental health problem.

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