



Working with people who hoard

Introduction

Hoarding has become increasingly acknowledged as a widespread challenge for practitioners in social care and allied sectors. Its consequences can include:

- > severe emotional distress and/or relationship breakdown
- > significantly restricted social and home living activities
- > poor sanitation, with resulting health risks
- > increased danger of fires
- > the possibility of eviction.

While no comprehensive costs estimates are currently available, it is clear that the impact of these consequences on individuals, families and society is significant (Tolin et al, 2008). At the same time, people may hoard for many reasons, which sometimes include seeing it as useful, pleasurable or a way of coping. Therefore, they may or may not wish to make changes. Practitioners must find a balance between respecting the person's choices and addressing the risks with them.

Work with hoarding has been affected by important changes to both policy and diagnostic guidance.

- > Firstly, statutory guidance issued in support of the *Care Act 2014* specifically refers to hoarding as one of the behaviours that can constitute self-neglect (Department of Health, 2016). Self-neglect, in turn, is listed as a form of abuse or neglect that may raise safeguarding concerns. Hoarding may therefore be referred to safeguarding where appropriate; otherwise it may be addressed through adult social care (see *Legislation and Guidance* section on page 12).
- > Secondly, 'hoarding disorder' has been identified as a new psychiatric diagnosis in the fifth edition of the American Psychiatric Association's *Diagnostic and Statistical Manual*, or *DSM-5* (American Psychiatric Association, 2013), boosting its recognition as a mental health issue.

Both developments have implications for practitioners' responsibilities. Hoarding challenges those involved to address risk while working with the person's strengths, wishes, feelings and beliefs. Such an approach is in line with *Care Act* principles of wellbeing and Making Safeguarding Personal.

This briefing looks at:

- > what hoarding is, and why people hoard
- > assessment, intervention and risk-management in hoarding
- > legislation and guidance relevant to hoarding
- > coordinating multi-agency working in hoarding.

What is hoarding?

Estimates of hoarding prevalence vary. Recent studies carried out in European countries suggest that between 2.3 per cent and 6 per cent of the general population may meet criteria for hoarding. Evidence from interview studies with people who hoard suggests that hoarding behaviours often start in childhood or adolescence, but may not develop into moderate or severe hoarding until later in adulthood. Hoarding is found across socioeconomic classes. Men and women are thought to be equally likely to hoard (Steketee and Frost, 2014).

Hoarding is distinct from 'collecting', an activity not usually associated with the harms that result from hoarding. A person who hoards:

- > experiences great difficulty in getting rid of their possessions, which may or may not have value in the eyes of others
- > left to themselves, fills living areas with clutter so that they can no longer be used as intended
- > experiences significant distress
- > experiences restrictions to social, occupational or daily living activities, and/or presents significant risk to their own safety or that of others, because of the hoarding.

Many people who hoard continue to acquire additional items despite lack of space (Mataix-Cols and Pertusa, 2012).

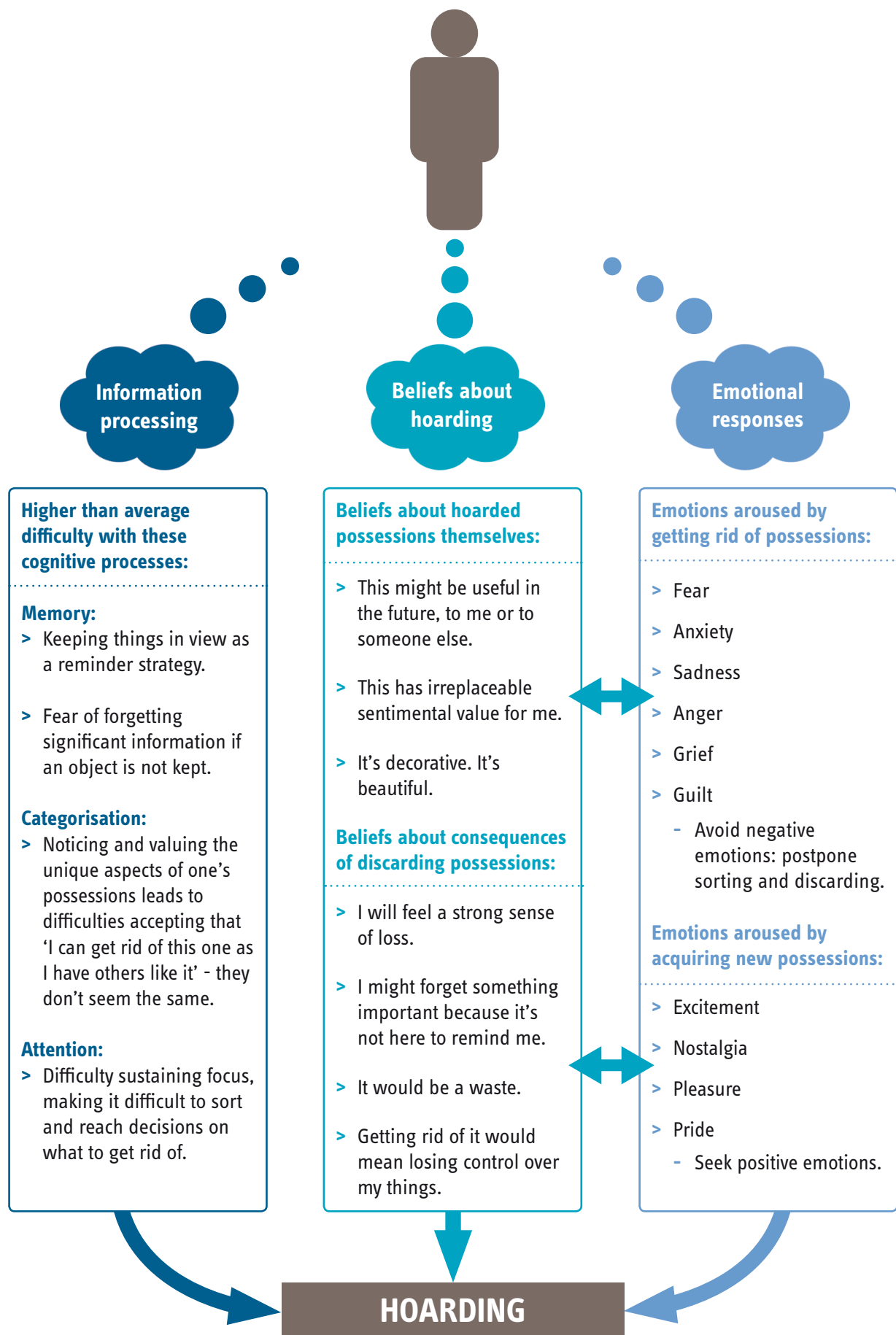
People may hoard a variety of different things, for a range of reasons. Often they accumulate common items such as papers, household objects or consumables. Some people have been known to hoard organic matter, such as bodily waste (for example nail clippings, faeces, etc) or rotten food; this is often linked to Obsessive-Compulsive Disorder (OCD) (Pertusa and Fonseca, 2014).

However, the presence of organic waste does not always indicate OCD, as squalor may build up in a hoarding situation without being deliberately hoarded. In particular squalor often occurs as a by-product of 'animal hoarding.' This occurs when the person keeps large numbers of animals as pets, but fails to care adequately either for the animals or their environment (Norberg and Snowden, 2014).

Why do people hoard?

According to the cognitive-behavioural model of hoarding, three factors – information processing, beliefs about hoarding and emotional responses – combine to produce hoarding behaviour (see diagram on following page). Hoarding may result from difficulties with specific cognitive tasks requiring information processing, or be a strategy for dealing with these difficulties. The person develops beliefs about their possessions, sometimes because of these difficulties. They experience emotional reactions to the loss or acquisition of possessions, which in turn reinforces particular beliefs about the effects losing or gaining items may have. All three dimensions interact in entrenching hoarding.

This model provides a useful way of conceptualising the thought processes linked to hoarding. However, each person's reasons and behaviour are individual, and the model should therefore not be applied uncritically. Rather, it is best used as an aid to understanding, alongside enquiry into the person's feelings, social context, biography and motivations.



Adapted from Wheaton (2016)

Perspectives of people who hoard

Research is ongoing into how such beliefs and emotions become habitual in the first place. Hoarding has been linked to having experienced traumatic life events. Surrounding oneself with possessions, or 'clutter', may in some cases be an attempt to reconstruct a sense of security. There is also evidence that hoarding shows strong familial heritability, whether through upbringing, genetic pathways, or both (Kyrios, 2014). Both these findings point to the importance of considering the person's life history within assessment.

Hoarding and other conditions

Some medical or mental health conditions can also give rise to hoarding (Pertusa and Fonseca, 2014). These include:

- > Obsessive-Compulsive Disorder (OCD)
- > Acquired Brain Injury
- > Autistic Spectrum Disorder
- > Dementia
- > Depression
(Hoarding often accompanies depression because of lack of energy and motivation, leading to inability to control clutter and discard items, rather than because of a tendency to hoard for its own sake.)

Comprehensive assessment should evaluate whether other conditions or disabilities may be contributing to the hoarding, so that appropriate intervention can be planned.

While the model just described helps in understanding 'what might be going on' for the person who hoards, the particular strengths of social care practitioners lie in working alongside the person and engaging meaningfully with their perspectives.

People who hoard may hold varying views on their situations. Some find the 'clutter' distressing but have difficulty acting on it, while others do not feel their accumulation is problematic, though they may sometimes be distressed by others' reactions and the risks of eviction or environmental health actions (Braye et al, 2014).

In studies (Braye et al, 2014; Kellett et al, 2010), people have reported that they perceive their situation to be due to some of the following reasons:

- > Childhood experiences (for example not being allowed to keep possessions, emotionally distant relationships with adults, abuse).
- > A strong concern with ethical disposal of things and the avoidance of waste.
- > Close identification with objects or what they represent.
- > Keeping things in case someone else might need them.
- > The potential monetary or use value they see in objects.
- > A sense of achievement or self-worth bound up in the possessions (for example the collection as an achievement, or possessions as reminders/products of past successes).
- > Perfectionism (partial sorting is seen as worse than none at all, because it means things being disturbed without fully re-ordering; organising is only worth doing if it can be completed in one go, and this proves difficult).
- > Lack of adequate storage and living space.
- > Having different standards of tidiness and order to those of majority norms, not conforming.
- > Objects as reminders of past, or sometimes present, relationships.

"I want things that belonged to people so that they have a connection to me."

"We – people who self-neglect – we cling on to our triumphs."

"Everything in my eyes [...] has potential use."

(Braye et al, 2014)

Those who find their own hoarding distressing sometimes report being 'overwhelmed' or 'gridlocked' at the prospect of trying to deal with the mass of things they own (Braye et al, 2014). For others, the effects on other people are as, or more, distressing; they fear being thought strange or describe how family members or friends can feel 'driven out' by the hoarding (Braye et al, 2014; Kellett et al, 2010). Some feel 'terror' of being found out by landlords or authorities and the consequences that might ensue (Braye et al, 2014).

What people who hoard say they find helpful

- > Take the time to understand us.
- > Avoid making us feel defensive.
- > Focus on us as people, rather than just our problems.
- > Show a sense of timing - recognising when we might be ready to change.
- > Move at our pace.
- > Be careful to avoid body language or comments (for example "You've got a lot of stuff!") which might seem judgemental.
- > Be honest about the possibility of imposed measures (see *Legislation and Guidance* section on page 12).
- > Avoid presenting imposed measures as threats to get our compliance.
- > Find the balance between 'encouragement' and 'pushiness'.



Questions for reflection

- > How do I build relationships that will help me find out about people's reasons for accumulating possessions?
- > What does a person-centred approach mean in terms of the words and actions I might use to reduce anxiety caused by my presence and help to build trust?

Assessment

Assessment should explore the history of the hoarding, and the person's beliefs, values and goals in relation to it. The views of family members and others affected should be sought wherever possible and appropriate. The predominant approach to hoarding focuses primarily on deficits and may lead to the person's strengths being overlooked, so it is important to identify these and seek to build on them. For example, the person's reasons for hoarding might include an environmentally-aware hatred of waste, or creativity in seeing potential uses for items that others would just discard; these motivations deserve to be given acknowledgement and due recognition (Braye et al, 2014).

Thorough risk assessment is equally important.

Factors to consider in risk assessment:

- > The person's awareness of, and attitude towards, the risks.
- > Fire risk, sanitation, hygiene, structural safety and obstruction of entrances/exits.
- > Degree to which hoarding interferes with daily activities.
- > Mental or physical health issues, disability - do these increase hoarding risks?
- > Strengths and protective factors.
- > Risk posed to others in household, or to neighbours.
- > Dynamics of the relationship(s) with any carer or other involved third party.
- > Mental capacity to make decisions about the hoarding (see *Legislation and Guidance* section on page 12).

(Brown and Pain, 2014)

Assessment tools are available to guide decisions about risk. Currently, the most widely used is the *Clutter Image Rating Scale* (Frost, Steketee, Tolin and Renaud, 2008), a visual assessment tool that uses photographs of different levels of clutter to assist assessors by providing a standard for comparison. It uses a nine-point scale for each part of the home, divided into Low, Medium and High risk.

Practitioners should be prepared for the possible impact on them of an initial visit to a property where hoarding has taken place (Braye et al, 2014). The conditions can sometimes arouse concern or shock. For example, someone who dislikes confined spaces may find that the surroundings provoke anxiety.

It may sometimes be hard to engage people who hoard, and they may decline assistance. Social work skills and values are important in ensuring that practitioners, while respecting the person's autonomy, consider what may lie behind those decisions and attempt to explore them with the person. Where the person's decisions place them at significant risk, this should be discussed with them. Where risks are significant, a formal mental capacity assessment should be carried out and recorded. Thought may need to be given to whether and how some form of continued involvement can happen, rather than automatically closing the case (Braye et al, 2014).



Further reading

Research in Practice for Adults has produced a briefing on risk enablement which may inform the approach taken to working with risk:
McNamara R and Morgan S (2016) *Risk enablement: Frontline Briefing*. Dartington: Research in Practice for Adults.

Intervention

Depending on the outcome of assessment, different referral pathways might be considered. The precise route will be determined by a combination of:

- > the person's wishes and feelings, and individual circumstances
- > legal mandates (see *Legislation and Guidance* section on page 12)
- > local policies and services that deal with hoarding
- > levels of need and risk.

To be successful, work with people who hoard often requires a practitioner to build a strong relationship that can enable the search for negotiated solutions. Once trust is built, the person's willingness and ability to take action on their own behalf can be considered and reinforced. This may take time, as developing trust can easily be shattered by trying to move too quickly toward moving items, if the person has not yet given agreement (Braye et al, 2014; Brown and Pain, 2014).

Case study

Over a period of years, Simon had accumulated several tonnes of timber, scrap metal and other materials, which filled his flat. It was now only possible to move through the home using 'tunnels' and any maintenance had become impossible. Simon lived in fear of discovery and eviction, but more than the risk of homelessness, he was horrified by the thought of 'being judged' and the humiliation of seeing other people's reactions. Yet, at the same time, he drew great comfort from his possessions and felt that it would be a waste to dispose of anything.

Eventually Simon was notified that work had to be carried out and, fearfully, he admitted that the state of the flat made this impossible. When the authorities responded non-judgementally, he was relieved, and this formed the basis for development of a trusting relationship with a social care practitioner. Working at Simon's pace, the practitioner came to understand what mattered to him, and both he and Simon were able to recognise the gap that the possessions would leave in Simon's life.

Simon was encouraged to develop his interests and activities, and patience and acceptance were key in helping him to find a way to 'let go' of much of his stock. He finally allowed a specialist clearing contractor to remove more than half of it. His worries that the time he had spent collecting these items had been wasted, as he had not been able to put them to good use, were overcome by working towards new goals and achievements.

"[The group] lets you know that you're not the only one trying to get help [...] it kind of gives you a bit of peace of mind that you're not a complete out-of-space weirdo and that it is a lot more common than people realise."

Person using services, interviewed by Braye et al (2014)

People who hoard often find it very difficult to make large reductions in the 'hoard'. Therefore, the priority for practitioners is often harm reduction rather than complete clearance. Sometimes specific steps to reduce risk can be agreed (for example moving piled-up objects away from a heat source) that deal with the immediate risks, such as fire, while helping to build trust for working towards further changes (Braye et al, 2014). Motivational Interviewing techniques have been found to be helpful where individuals may be considering some level of change (Braye et al, 2014).

Support groups and both internet-based and print self-help resources exist for hoarding. These may provide valuable support and input for people who hoard at all levels of risk (Williams and Viscusi, 2016). A particular benefit may lie in providing members with a sense of acceptance and mutual support, which can counteract the 'shaming' they have often experienced (Brown and Pain, 2014).

De-cluttering services may be available in some areas to work with people who are motivated to change. Ideally, any intervention plan should consider how to build on the person's strengths, often by connecting them to a role or activity that is meaningful for them (see case study on previous page).

Hoarding disorder is now recognised as a mental health issue and a referral for therapy may, where the person wishes it, therefore be appropriate. Hoarding may sometimes co-present with other mental health issues, such as depression, which may in themselves be reason for a referral to primary care-based or specialist mental health services (Pertusa and Fonseca, 2014). The most promising existing intervention for hoarding itself is a multi-component cognitive-behavioural therapy-based model developed originally by Steketee and Frost (Wheaton, 2016), shown in the following diagram.

1. Assessment of symptoms and hoarding-related skill deficits, to develop a shared understanding with the person who hoards.



2. Identify person's values and goals to establish reasons for change, using Motivational Interviewing techniques. Avoid arguing about person's beliefs, treating them instead as hypotheses to be tested.



3. Skills training that focuses on using systems for sorting, categorisation techniques and attention training for staying on task.



4. Cognitive Behavioural Therapy (CBT) techniques to help the person identify instances of distorted thinking.



5. Staged exposure to challenges which increase in difficulty, from visualisation through to trying out discarding and resisting acquisitions.



6. Review progress, consolidate, plan to avoid relapse and develop strategies for future clearing.

Adapted from Wheaton (2016, originally developed by Steketee and Frost)

Social care practitioners might use this intervention if sufficient time is available for their ongoing involvement and they have sufficient knowledge (see *Further reading*). Even if not, they should be aware of the outline so that they understand the general approach and can reinforce it with the person where appropriate.



Further reading

The British Psychological Society Division of Clinical Psychology (2015) *Good Practice Guidelines for Hoarding* provides much useful advice on understanding and working with hoarding. Available online:

www.bps.org.uk/system/files/Public%20files/a_psychological_perspective_on_hoarding.pdf

Gail Steketee's and Randy Frost's books provide a detailed account of using this model in practice:

Steketee G and Frost R (2013) *Treatment for Hoarding Disorder: Therapist Guide*. Oxford: Oxford University Press.

Steketee G and Frost R (2013) *Treatment for Hoarding Disorder: Workbook*. Oxford: Oxford University Press.

Landlords and authorities sometimes enforce complete clear-outs or deep-cleans against the person's will, using legal mandates. Environmental health or other concerns may sometimes make this unavoidable, but it should be a last resort as it is usually very traumatic for the individual affected. Often it leads to a breakdown of trust with services as a whole and does little to provide a long-term solution as the person subsequently returns to the same patterns of behaviour (Brown and Pain, 2014).

"We go in, do a clearance, it gets left; a year, two years later, we have to go back in again."
(Practitioner interview, cited in Braye et al, 2013).

Clearances should therefore ideally be done with the permission and participation of the individual.



Further reading

Help for Hoarders is a UK-based website which provides self-help advice, information about some local support groups and discussion forums for issues relating to hoarding:

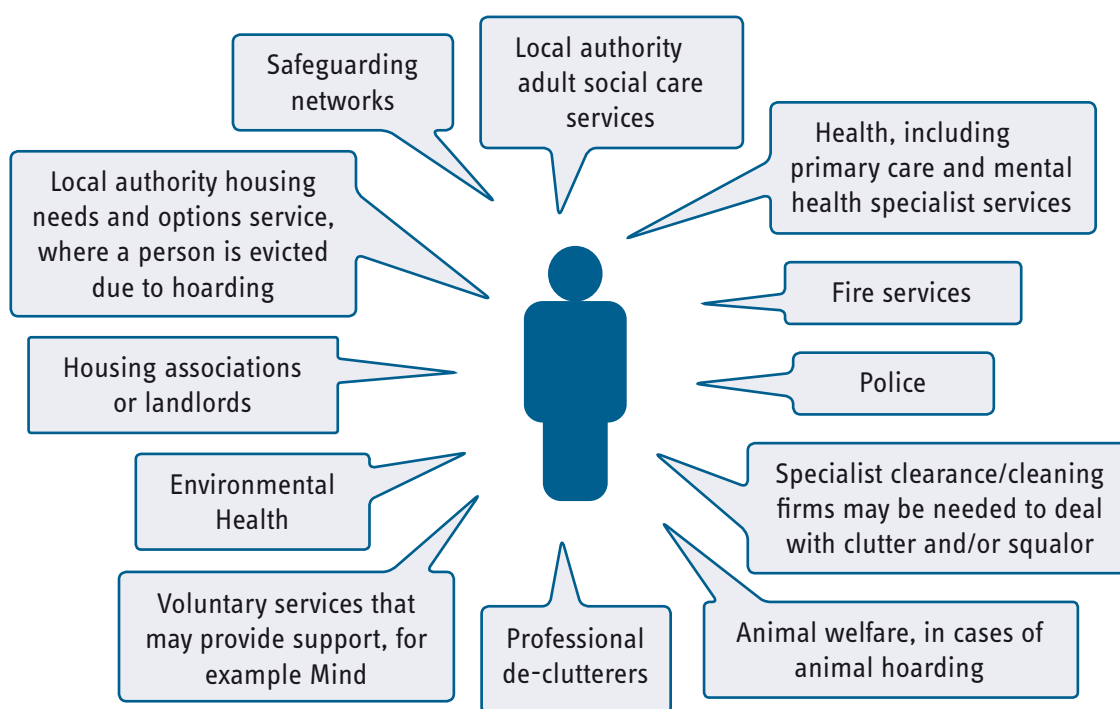
www.helpforhoarders.co.uk

The Association of Professional Declutterers and Organisers holds a directory of registered de-cluttering services. Not all de-clutterers are confident in working with significant hoarding. However, some have developed considerable experience and work with local authorities to support people who hoard:

www.apdo-uk.co.uk/resources.php/hoarding

Multi-agency working in hoarding

A number of different agencies and individuals may become involved with people who hoard. These may include some or all of those shown here:



Practitioners should follow multi-agency arrangements in place in their locality. Serious Case Reviews and the research literature repeatedly highlight the importance of agreeing a clear lead agency and a coordinated plan between the agencies involved, to ensure that service responses are proactive, and that different perspectives on the situation, its risks and the person's motivations have been taken into account (Braye et al, 2015; Brown and Pain, 2014; Koenig et al, 2010).

Different views on hoarding are often held by practitioners working in different agencies. This makes it all the more important that forums exist for the exchange of information and views, and agreement on a shared plan. Social workers or social care practitioners may play a particularly important role as mediators by bridging different positions and advocating for the person's needs and views (Brown and Pain, 2014).

Information sharing between agencies should be proportionate to the risks involved. In particular, where imposed legal measures are being considered on safeguarding, environmental health, tenancy or animal welfare grounds, it is important that the practitioners involved are aware of what may happen and its timing, so that they can plan what support may be needed.



Questions for reflection

- > How does my role in working with this person influence how I view the hoarding?
- > What does the person see as my role in relation to the hoarding?

Legislation and guidance

A range of legal rules underpins intervention in hoarding; adult social care and relevant partners play a key role in identifying needs, and in some cases power and duties held by other agencies are also engaged. The Safeguarding Adults Board (SAB) plays a key role.

The SAB has a statutory duty (s.43, *Care Act 2014*) to help and protect adults with care and support needs experiencing abuse and neglect and unable to protect themselves.

It must coordinate and ensure the effectiveness of what each of its members does.

Underpinning all actions taken using legal powers and duties is the responsibility of public authorities under the *Human Rights Act 1998* to promote the rights set out in the European Convention on Human Rights. Particularly relevant are:

- > the right to respect for private and family life (article 8)
- > the right to liberty and security of the person (article 5)
- > the right to protection from inhuman and degrading treatment (article 3)
- > the right to life (article 2).

While (with the exception of article 3) rights may be breached in certain circumstances, any interference must be in accordance with law, necessary and proportionate.

Assessing need

Section 9, *Care Act 2014*:

Local authority duty to assess care and support needs where it appears an individual *may* have needs for care and support, regardless of their nature or level.

Section 42, *Care Act 2014*:

Local authority duty to make enquiries where (a) an adult has care and support needs, (b) is experiencing or at risk of abuse and neglect and (c) as a result of their care and support needs is unable to protect themselves.

Which route to follow will depend on a case-by-case evaluation of the most appropriate way forward. Statutory guidance (Department of Health, 2016) supports this discretion, implying that it is where the adult is unable to control their own behaviour without support that a safeguarding response is required. The two routes are not mutually exclusive; if a s.42 enquiry is the starting point, it could lead to a s.9 assessment. Regardless of which route is taken, additional *Care Act 2014* duties apply:

An advocate must be appointed if the person appears to have difficulty understanding the process and expressing their wishes and feelings, and has no-one else to assist them - sections 67/68.

It must be assumed the individual is best placed to judge their own wellbeing; due regard must be paid to their views, wishes, feelings and beliefs - section 2(3).

The wellbeing principle (section 1) must underpin the local authority's actions; statutory guidance emphasises its importance in self-neglect (Department of Health, 2016).

If a carer is involved and it appears they may need support, they should be offered a carer's assessment under s.10 of the *Care Act 2014*. The focus will be upon their willingness and ability to provide care, and the impact of providing that care on their own wellbeing.

In relation to all local authority functions under the *Care Act 2014*, there is a reciprocal duty of cooperation between the local authority and relevant partners (s.6 relating to strategic level cooperation and s.7 relating to cooperation in individual cases), which can be drawn upon to secure agencies' participation.

Care and support needs assessment must be followed by a determination of which needs are eligible to be met (s.13). Maintaining a habitable home environment and using it safely are two of the specified outcomes likely to be compromised in severe hoarding.

A care and support plan must be made, identifying how eligible needs are to be met (s.25) and a personal budget allocated (s.26); the plan must be kept under review and revised if circumstances change (s.27).

Eligible needs are those that arise from physical or mental impairment or illness (formal diagnosis not required) as a result of which the individual is unable to meet two or more outcomes, with significant impact on their wellbeing.

Assessing capacity

As part of a needs assessment or a safeguarding enquiry, it is important to evaluate the individual's mental capacity, observing the statutory principles (s.1) and duties set out in the *Mental Capacity Act 2005*.

Capacity must be determined in relation to a specific matter at a specific time; in hoarding it will be important to identify whether the individual has capacity to understand and make decisions about the risks involved in the situation, and to make daily living decisions that enable them to meet their personal safety needs, for example having adequate nutrition and hydration, using sanitation facilities and avoiding injury or infection.

Assessment of mental capacity requires the application of the two-stage test (s.2):

Does the individual have an impairment of, or disturbance in the functioning of, the mind or brain...



...as a result of which they are unable to make the specific decision at the specific time, ie are unable to understand, retain or use and weigh relevant information or to communicate a decision (s.3)?

If mental capacity is lacking, the statutory process for determining what is in the person's best interests decision must be followed (s.4), with additional safeguards if provision of care and support entails deprivation of liberty.

Powers of entry

In certain circumstances it may be necessary to secure entry to premises if refused (please note that **the following applies to England only**, Scotland and Wales have devolved arrangements).

<i>Mental Health Act 1983</i>	<i>Police & Criminal Evidence Act 1984</i>
Magistrate's warrant if it is believed someone is mentally disordered and is being ill-treated or neglected, or lives alone and is unable to care for themselves, authorising the police, accompanied by an approved mental health professional (AMHP) and a doctor, to enter the premises.	In a genuine emergency (not in response to general concerns about welfare), the police may enter premises without a warrant to save life or prevent injury, or prevent serious damage to property.

Mental health

The *Mental Health Act 1983* also provides powers and duties where the individual has mental health needs.

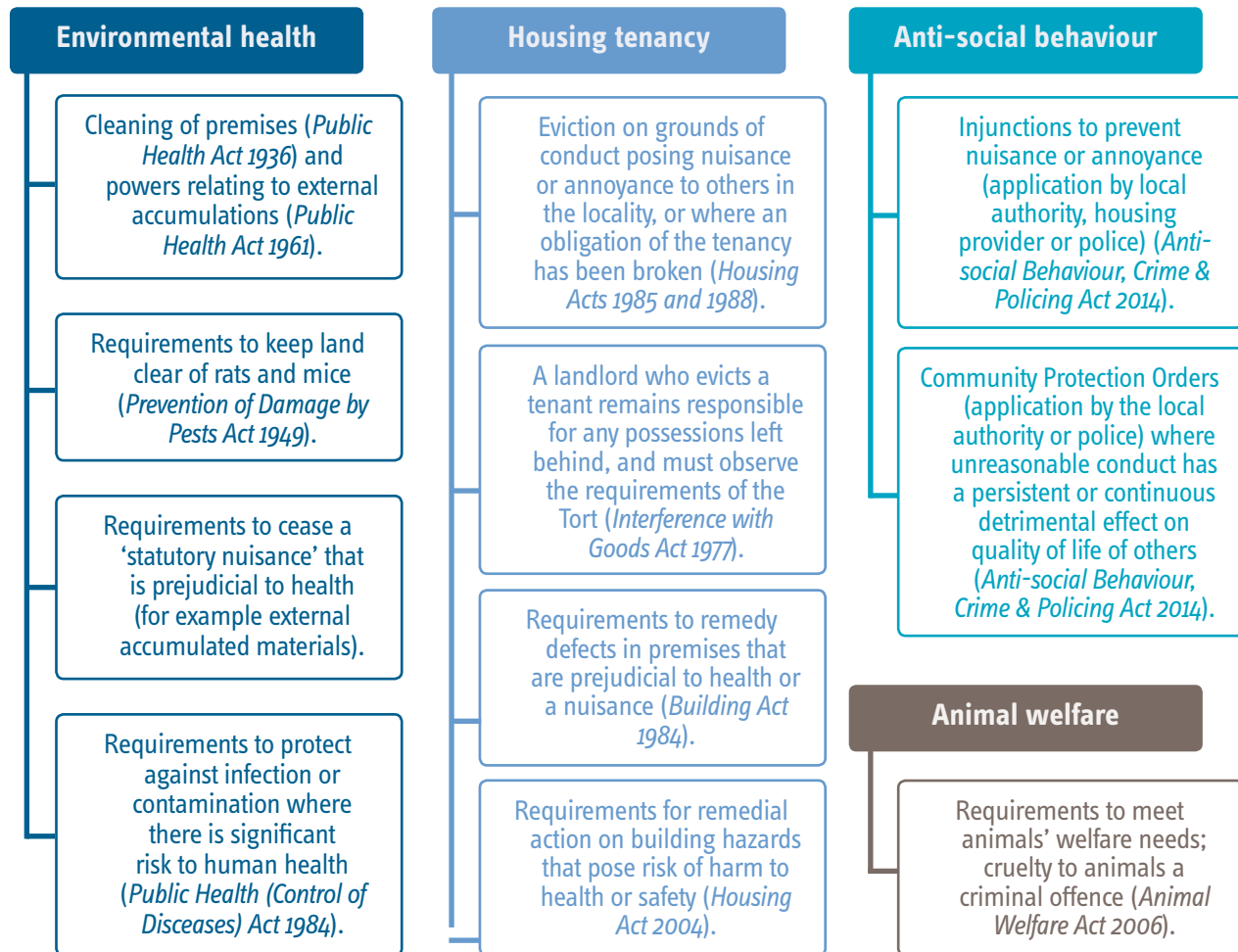
Where the individual has a mental disorder of a nature or degree that warrants admission to hospital, and admission is in the interests of their health or safety or for the protection of others, an AMHP or their nearest relative may make an application for admission for assessment (section 2) or for treatment (section 3) (where treatment is available and can only be provided under detention).

Guardianship (s.7) may be an alternative to hospital admission where an individual has a mental disorder of a nature or degree that warrants reception into guardianship, and such a relationship is necessary in the interest of their welfare or for the protection of others.

The inclusion of hoarding disorder as a psychiatric diagnosis within DSM-5 arguably makes such an intervention a possibility in situations where the hoarding is not attributable to another medical condition or better explained by the symptoms of another mental disorder.

Beyond adult social care

In circumstances where an individual is assessed as retaining capacity to make relevant decisions and all attempts to build a relationship of trust have failed to secure their cooperation with a risk management strategy, wider legal rules apply, permitting intervention primarily to protect others from the risks that arise from an individual's behaviour.



Court jurisdiction

The courts provide avenues for resolution of uncertainties and dilemmas:

- > The Court of Protection where an individual lacks capacity or where capacity is uncertain.
- > The High Court where an individual who otherwise has mental capacity is prevented from exercising that capacity freely due to constraint, coercion or undue influence from someone else.

Conclusion

Everyone who hoards has their own reasons and story. Practitioners require knowledge, empathy and persistence in order to build the relationships that will allow them to hear those stories and work effectively with individuals. It is important to understand the person's perspective and build trust with them, while acknowledging and acting on the risks that may be present. Knowledge of the legal framework shaping social care and safeguarding provides guidance on how this balance may be negotiated in practice.

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