

# 1



## Introduction

### SUMMARY

This chapter starts with a look at the concept of hoarding, beginning with what it is and how some animals and most people have a tendency to collect items beyond their immediate requirements. The distinction is made between a hoard and a collection. The types of items which are hoarded are discussed, along with a description of Animal Hoarding.

Some of the social aspects of hoarding are discussed, as it is easier for hoarding to get out of hand in a small bedsit as opposed to a large mansion with more available space. We will address the stigma of hoarding and how this can be treated by society, along with discussion of the shame and humiliation which prevents many people with hoarding problems from seeking help. This stigma can be reinforced by “helping” agencies who may view it as a “lifestyle choice” rather than a condition which requires help, and we look at the role the media has played in perpetuating the myth that hoarders should be able to deal with it themselves.

Hoarding can be regarded as a symptom rather than a distinct diagnosis and may be found in many conditions, but there is a specific condition with characteristic features known as Hoarding Disorder. Some possible causes of hoarding are then described, followed by a more detailed examination of the diagnosis of Hoarding Disorder.

Finally, the chapter examines whether hoarding only occurs in the elderly, and introduces the idea of hoarding in childhood.

## What Is Hoarding?

If you look up the term “hoarding” in a dictionary, it is described as the act of keeping large amounts of food, money, or other items, and that this is often hidden from other people. Obviously, this is not a straightforward definition as most of us would prefer not to live “hand to mouth” but to store a little more for the future in case of times of greater need. Examples of this include pickling and preserving food in the abundant summer months to ensure food was available over winter in the days before freezers and refrigeration. Similarly, most of us would like to have a little more money in the bank over and above our daily outgoings if we are in a position to do so. Indeed, we are not the only animal that likes to do this. Most people will have observed squirrels burying nuts and seeds for the winter or in times of excess, only for some of these storage places to be forgotten or the contents not needed by the squirrel, and what we will see is a horse chestnut or similar sapling growing in the garden even if we are well beyond the distance where the tree would normally drop its fruit. Domestic dogs will also try and bury particularly tasty morsels of food if given a treat while not hungry at the time, and may then reappear with a maggot-infested biscuit or bone some weeks later.

## Does Hoarding Matter?

We can therefore see that all of us do have a tendency to save up items and to store them for times of greater need. Such activity is usually considered prudent and a way of protecting our future. Excessive hoarding, however, can be an extremely dangerous problem even resulting in death due to the increased fire risk. If you look through a local paper, it is not unusual to see house fires reported, and if you delve a little deeper, you can find out that a high proportion of these occur in houses which are cluttered, where the occupants have obtained a large number of flammable objects. For example, it was reported that, in 2022, the London Fire Brigade attended 1036 hoarding-related fires which resulted in 186 injuries and 10 deaths.<sup>1</sup>

In Wales, it was reported that hoarding was responsible for 25–30 per cent of fire-related deaths.<sup>2</sup>

As well as fires, deaths and injuries can occur when a large quantity of items causes someone to trip and fall, or when they become trapped under an “avalanche” of possessions.

Although deaths and serious injuries are a dramatic portrayal of the difficulties that can arise from excessive hoarding, there are other more mundane effects which impact on an individual's mental and physical health.

Hoarding was not recognised as a diagnosis until 2013, but there were reports in the medical literature from the middle of the 20th century of what was described as “Diogenes Syndrome”. This was mainly being described in older people and was said to consist of excessive hoarding, self-neglect, and living in squalor and unsanitary conditions. Hoarding is likely to lead to self-neglect as well as unclean conditions. If a home is full of hoarded items, then you may be unable to wash and take care of basic self-care routines. Similarly, it may be impossible to access the fridge and cooker to cook a reasonably healthy meal. Cleaning becomes impossible as objects accumulate and cover every surface. In addition, there is the possible detrimental effect of what is hoarded, so that, for example, if perishable items are contained amongst the hoard, there may be vermin including insects, maggots, rats, mice, or even other animals. Then, as a final point, if someone is spending a considerable proportion of their income on items that are hoarded or, in many cases, on renting additional space to keep their hoard, then they are likely to have a lack of money for food and heating and their health will suffer accordingly.

### *Jill's Story*

Jill is a 50-year-old unmarried woman who lives alone in a large detached home. Despite gaining an excellent degree at university, she has never worked due to intermittent bouts of severe depression. It was during one of these episodes of depression when she was hospitalised that there were complaints

from her neighbours about a smell emanating from her large suburban villa. Although Jill had never worked, she had inherited both property and money from her family and lived in an affluent part of town. Discussion was held with her and eventually, after a few weeks of discussion, she extremely reluctantly agreed that one of the therapists she trusted from the local community mental health team could accompany her on a home visit.

On entering the house, the therapist found that it was full of papers and other items with just a narrow passageway through the house. All four of the bedrooms were piled high and impossible to enter and the bath was full of objects with barely room to access the toilet. It was in the kitchen where there was the biggest surprise, as there was a strong smell and it appeared that rotting food was intermixed with the papers and other items. It was impossible for Jill to have used this space for cooking for many months or even years. As they entered the kitchen, however, a fox darted out from under the piles of accumulated items and ran through a broken window into the garden. It transpired that a family of foxes was living under the hoard in the kitchen along with rats and mice.

## What Do People Typically Hoard?

**While most people hoard objects which either have a practical purpose but the amount is excessive, for example, food, newspapers, etc., or which have an emotional meaning to them, for example, items from a deceased family member, others may hoard in different ways.**

### *George's Story*

George is a 45-year-old unmarried man who lives on his own in a small housing association apartment. As a young man, he had hoped to become a film critic for one of the major national newspapers, had studied journalism and film after school, and had landed a job as the arts correspondent for a small local paper. However, the local paper was bankrupt after a few years and George had been unable to find permanent work for the previous 10 years. Still having an avid

interest in film, George spent money attending as many shows as possible. He also collected what he described as “film reviews” but which in fact were copies of every major newspaper which had a film section. These newspapers were piled high throughout his flat. On questioning, it appeared that George was in a considerable amount of debt, and as well as having a house full of old newspapers, he also had hired a lockup garage as well as three large containers at the local storage depot. The costs of hiring all this extra space as well as the purchase of every national newspaper every day exceeded his income, and George was pale, thin, and self-neglecting and clearly not eating sufficiently well to maintain health. He was insistent that these newspapers were a “comprehensive collection of film reviews” even though they were complete papers stacked in random piles with no attempt at classification or order, and he was unable to say where any particular review might be found.

One of the most distressing forms of hoarding is Animal Hoarding. This is most commonly seen by people working with animal charities. In these cases, the individual collects large numbers of animals who they may believe they have rescued, but in reality they have too many animals to care for appropriately and there may be many sick, neglected, or even dead animals.

### *Jean's Story*

Jean is a 50-year-old woman who has always had a passion for animals and always had one or two dogs in her home at any one time. Ten years ago, her partner of 15 years left her for another woman, and Jean was left bereft. At approximately the same time, her elderly dog died. Friends encouraged her to adopt another dog from a dog rescue charity. At this time, Jean became fascinated by the charity and began volunteering for them. After a couple of years, she decided to set up an animal rescue in her own area. In the past, she had tried to adopt a variety of animals, but her partner had stopped her accumulating too many by insisting she place them elsewhere. Once Jean

set up her own animal charity, she became more and more reclusive and was rarely seen out and about by neighbours and friends. She'd started walking her dogs very early in the morning and very late at night. Neighbours became concerned that the house was in a state of increasing dilapidation, and the noise from the animals was a cause of concern. Eventually the neighbours complained about the noise to the police. A local policeman was called, and he explained to Jean that her animals were disrupting her neighbours' sleep by the noise. Jean became very abusive on hearing this and shut the door. Being concerned about what he saw through the door, the policeman called the Royal Society for the Prevention of Cruelty to Animals (RSPCA). Two days later the police returned with the RSPCA and they tried to speak with Jean and asked to see her animals. Jean was adamant that all her animals were "fine" and that she loved them all dearly. However, the smell emanating from the house was overwhelming and a dog that was seen in the doorway appeared emaciated. The RSPCA officer informed Jean that he was concerned about her animals and would like to see all of them. At first Jean denied anyone entry but, when it became clear to her that the police and RSPCA were looking to collect evidence for a court case, she reluctantly let them in. They found she had 30 dogs in a tiny space, and the floors and carpets were covered in faeces. All the dogs looked unhealthily thin. When asked when the dogs had been seen by a veterinarian, Jean said that she had not taken them. She tearfully expressed how much she loved her dogs and begged the RSPCA not to take them from her as she believed she had a special bond with each and every dog and that no one else could care for them in the way she did. Eventually it was agreed that the RSPCA could return with a veterinarian. Over the next few weeks, plans were made to encourage Jean to agree to let some of her dogs be rehomed elsewhere. Sadly this occurred by threatening her with court action, which would have meant prosecution and her losing the right to keep any animals.

**Sadly, unlike with object hoarding, most people who hoard animals are still dealt with via the courts as many are unwilling to work with the animal charities, so the only course of action to protect the animals is via legal pathways. Similarly, very few people with animal hoarding issues are seen by mental health services; therefore, there is little**

research in this area. Most descriptions and research regarding Animal Hoarding have been published in veterinarian publications, and is animal-focussed.

## Is There Any Difference between a Collection and a Hoard?

Some people collect items which may be of little interest and perceived as being of low value to others. For example, a collection of railway timetables, stamps, football stickers, etc., will be seen as very valuable to those who are interested in the area but not to other people. The question then arises as to what makes a collection different from a hoard.

In a collection, even if it is large and unwieldy, there is usually some kind of categorisation so that the collector can find an individual item without too much difficulty. On the other hand, a hoard is generally chaotic without any real categorisation or ability of the individual to easily find a particular item.

For example, in the story of George in this chapter, we described a man who collected huge quantities of newspapers due to his interest in film reviews. However, these were huge piles of newspapers and were not categorised in any particular way. Contrast this with James, who is also interested in film reviews. James also collects all the major newspapers on a daily basis. He reads the film reviews and cuts out the relevant articles. These articles are then put into plastic pouches and filed by date. In both cases, the items collected are film reviews from newspapers, and in both cases, these would be considered worthless and maybe excessive by others who do not share this interest. The main difference lies in the categorisation and ability to find specific articles. Even if George had cut out the various reviews from the newspapers, unless he had organised them they would still create a chaotic mess, even if it would have taken him longer to fill up so much space.

So we can see that organisation to enable retrieval is a characteristic of a collection rather than a hoard.

## Socioeconomic Aspects of Hoarding

Obviously, there are differences in the ability of someone to run out of space if they live in smaller spaces than if they live in a large mansion. Similarly, it is easier for someone on a lower income to get into debt in trying to maintain their hoard by either excessive purchasing of items or by needing to rent additional space to store them. In the case of Animal Hoarding, a very rich person may be able to accumulate a large number of animals but still afford to maintain them in a good state of health.

Differences also arise about concern about hoarding. It is much more likely that an individual who lives in close proximity to others, such as in a block of flats, will be reported to the authorities for hoarding issues than those who live more isolated lives in larger detached properties.

All of this means that we may have a skewed idea of hoarding, as those with lower incomes may be more likely to be reported to the authorities and be seen by mental health services.

Due to the shame associated with hoarding, few people come forward for help. Most people with hoarding difficulties are discovered by neighbours, friends, and family or after an event such as a fire or complaints about smell or objects blocking outside spaces.

## Stigma Associated with Hoarding

Unfortunately, huge stigma exists about hoarding. While this is sadly true of many mental health conditions, it seems to be particularly true about hoarding. As a condition, Hoarding Disorder was not officially recognised as a mental illness until 2013. There is still a tendency to blame people who hoard and to portray them as lazy, slovenly, and dirty. This is hugely unfair and leads to huge suffering on the part of the person with hoarding difficulties.



In the media, there have been many television programmes which portray hoarding as a joke, or someone who hoards as being deliberately difficult. Add to this that, until recently, many mental health services would consider hoarding as a lifestyle choice rather than a disorder.

Given this stigma, it is unsurprising that many people with hoarding problems are unwilling to seek help and unable to admit to a problem.

## What Are the Causes of Hoarding?

Although since 2013 there has been a diagnosis of Hoarding Disorder, it is important to remember that hoarding is a symptom which can be present in a range of physical, emotional, and mental disorders.

Hoarding may arise due to physical problems with discarding items, for example, lack of mobility meaning inability to discard items; lack of ability and motivation to face the problem, for example, severe depression, substance addiction; an inability to sort and categorise items, for example, issues such as dementia or certain types of learning disability; fear of harming oneself or others by discarding items, for example, Obsessive Compulsive Disorder (OCD) as well as being a prominent feature of Obsessive Compulsive Personality Disorder (OCPD) and, of course, Hoarding Disorder itself.

There is further discussion of conditions which may result in hoarding but not be due to a true Hoarding Disorder in the next two chapters.

## What Is Hoarding Disorder?

In all healthcare disciplines, it is important that people understand what is meant by a particular diagnosis so that they can communicate with each other, research specific topics, and be fairly certain that the same condition is being researched. There are two main producers of these lists of

diagnoses, which feature lists of symptoms of what is required to make a diagnosis of any particular condition. The World Health Organization produces a list known as the *International Classification of Diseases*, with the most recent version (the 11th Revision, ICD-11) being released in 2022. Another list is the American Psychiatric Association's *Diagnostic and Statistical Manual of Mental Disorders*, 5th Edition (DSM-5), which was published in 2013 and has had several updates and revisions since then.

In 2013, the concept of Hoarding Disorder was included in the newly published DSM-5, which was launched in May of that year. To produce the list, groups of experts in different fields of study come together to agree on lists of symptoms and diagnoses. DSM-5 introduced the new category of Hoarding Disorder, which is included in a section headed Obsessive Compulsive and Related Disorders.

This addition of Hoarding Disorders as a separate diagnosis is important, as until then, anyone with the symptom of hoarding was automatically placed in the diagnosis of OCD or Obsessive Compulsive Personality Disorder (OCPD), and there was no real research examining the characteristics, treatment, and response to treatment of people with Hoarding Disorder. Over a decade later, we now have much more information about this condition.

Hoarding Disorder is described in DSM-5 as persistent difficulty in throwing or giving away items irrespective of their real value to others. This difficulty in parting with objects is due to an urge to save items, and distress caused by parting with them. This difficulty in discarding leads to a cluttered environment which means that it is impossible or very difficult to use the rooms in a house for their intended use, for example, the bath is full of items or there is no space to sit in the living area. The hoarding causes difficulty in carrying out normal activities, or places the individual or others in danger. The hoarding should not be explained by another medical or psychological condition, for example, brain injury or OCD.

***Beatrice's Story***

Beatrice is a 75-year-old unmarried woman who lives in a housing association property. The housing association became involved when neighbours complained that boxes in the communal area outside her flat were creating a nuisance and limiting their ability to move around or to reach the fire escape in the event of an emergency evacuation. The fire service was asked to pay a visit and to assess the situation. When they arrived at a prearranged time together with representatives from the housing association, Beatrice was initially helpful and agreed that she would move the boxes. However, when it was suggested that she let the group into her flat, she became angry and refused. She was told that it was in her rental agreement that the landlords could ask to enter the property if necessary at a prearranged time. A date was therefore set for a week away.

At this follow-up appointment, Beatrice was defensive and still refused admission. After very lengthy discussions, she did however agree that she would attend an appointment at her general practitioner (GP) and ask for a mental health assessment.

Her GP knew Beatrice well and was aware that she had been evicted by several private landlords in the past. She had always lived alone and was extremely reluctant to let anyone into her property, which was piled high with papers, books, and magazines. On previous attempts to help her clear her living space, she had claimed that losing her possessions was equivalent to being raped by the mental health team. She had no significant mental health history, although her GP had been concerned about her low mood in the past when she had been evicted. For many years, she had worked as a clerk but retired at the age of 60 years, and it appeared that her hoarding issues became worse after retirement as she would spend long periods of time perusing second-hand book shops and purchasing magazines, old papers, and books. The GP described how she had a good relationship with Beatrice but that, in general, Beatrice was a loner who avoided the company of others.

## Is Hoarding Purely an Issue of Older Adults? What about Hoarding in Children?

We have already discussed how there has been a lack of research in hoarding in adults over the years and how often it was included under OCD even when there was no evidence of clear obsessions and compulsions.

When adults with significant hoarding problems and Hoarding Disorder are questioned, they frequently say that they first started to hoard items in childhood. There are no good studies of Hoarding Disorder as a standalone issue in children.

Childhood hoarding is unlikely to be a major problem, as parents will tend to oversee discarding and clearing of their living areas. Also, for any items that need to be purchased, parents or guardians are likely to be in control of the money that a child receives. This means it is unlikely that children will present for help with a serious hoarding problem. In a study from Turkey, the authors asked parents of schoolchildren to complete a screening questionnaire for hoarding problems. This was followed up by interviews. It was discovered that almost 1 per cent of the children demonstrated significant hoarding behaviours. Of those who had hoarding behaviours, girls appeared to be three times more likely than boys to be diagnosed with hoarding, and over half had evidence of another mental disorder.<sup>3</sup>

Children who hoard have been noted to be more likely to have diagnoses of Attention Deficit Hyperactivity Disorder (ADHD), OCD, or anxiety disorders.

Even though there is little research about children with hoarding problems, it is clear that it is an important issue which should not be overlooked. We know that, in general, if childhood mental illness is addressed early, the child has a generally good prognosis and is less likely to have severe problems in adult life. Greater awareness of the possibility of hoarding difficulties in childhood and adolescence and encouraging concerned parents to seek help is an important first step. Most adolescents can be untidy and may be lazy in throwing items away, leading to a disorganised

and cluttered bedroom. There is a difference, however, in that most teenagers would be quite happy to discard items which they don't need. Of course, some items that may be collected, such as football stickers, seem to have little actual value to someone who does not follow football, but will be considered very precious by the individual collector. Parents need to decide whether they have a child with a normal disorganisation and passion for a particular study, or a more generalised issue with discarding of items. The following case story highlights the difference.

### *Wayne's Story*

Wayne is a 14-year-old adolescent who loves football. Most of his conversation involves talking about football and he enjoys playing for his school team. Wayne's mother has two younger boys and separated from their father 7 years ago. Their father visits the children at weekends and takes them out, but he does not have space for the children to stay overnight. Their mother works as a school dinner lady but has more recently also started another job as a cleaner to try and improve their finances. In order to do this, she has asked the children to help with light housework in their own rooms. The younger boys share a bedroom, but Wayne has a room of his own. His mother became increasingly annoyed by the state of Wayne's bedroom. He never brought down dirty clothes for washing and his football kit was left for days and worn multiple times until his mother insisted he could not go to football with his smelly kit. In addition, there were half-eaten packets of crisps and biscuits, as well as dirty cutlery and crockery, strewn all over his bedroom.

His mother told Wayne he was not allowed to go to football training or matches until he cleared his bedroom. She warned him that she would inform his school football coach of the reason for his non-attendance. Although Wayne complained and shouted initially, the threat of his mother going to speak with the football coach meant that Wayne tidied his bedroom. It is far from perfectly neat and tidy, but if it starts to get out of hand again, his mother just has to remind him that she is happy to visit the football coach!

**SUMMARY**

- Some animals and all people often collect more items than is necessary for their immediate use, for example, pickling of vegetables to use over winter.
- Hoarding is an important cause of both ill health and even death by accidents and fires.
- Some people hoard a wide variety of objects and papers and some may hoard animals.
- Poorer people are more likely to be diagnosed with hoarding difficulties, whereas better-off people may be more able to hide the extent of their hoarding problems by purchasing/renting more space, and also because they may not live as close to others.
- Portrayal of hoarding in the media has frequently not been helpful and has undoubtedly added to the stigma associated with hoarding and the resultant shame, humiliation, and embarrassment experienced by those with a hoarding problem.
- Various physical, mental, neurodevelopmental, and psychological issues can result in hoarding as a symptom.
- Hoarding Disorder as a condition not caused by any other physical or mental condition was first fully described in 2013; therefore, there is little reliable research into the condition prior to this time.
- Hoarding Disorder involves accumulation of large amounts of items which the person has difficulty in throwing or giving away. This excessive accumulation results in difficulty using the living space fully due to accumulated clutter.
- Although often described in older adults, hoarding probably has its roots in childhood in most people. Living with others tends to reduce the side effects of hoarding, and it is later in life when more people are living alone that hoarding is seen.