



HOARDING DISORDER



Hoarding Disorder is a relatively new diagnosis in its own right, having only been recognised as a standalone disorder in the Diagnostic and Statistical Manual V which was released in 2013. Due to this there is unfortunately a limited amount of information on the condition and how many people it affects. However, hoarding is not a new behaviour and was instead previously thought to only occur as a symptom of other conditions. These conditions include Schizophrenia, Dementia and Depression, as well as physical conditions that limit one's ability to throw things away. However, the primary condition in which those with hoarding behaviours were thought to fit was Obsessive Compulsive Disorder (OCD). Whilst there are clear situations when hoarding is an OCD symptom, there is also a growing body of research and literature that highlight that not everyone with hoarding behaviours has OCD, which has led to the new disorder classification developing.

Throughout this brochure we will use the term hoarding to refer to Hoarding Disorder, as well as other instances of hoarding. Where we are using research that was based on old definitions of hoarding we shall highlight this to the reader. We hope this brief brochure will be of use to sufferers of hoarding, as well as their families and those who want to learn more. We will touch on what hoarding entails, as well as discussing the causes of hoarding, how common a condition hoarding is, and how hoarding is treated.

What is hoarding and how does it differ from collecting?

There are a number of different types of hoarding, some of which are specifically related to other disorders, but in general we can think of hoarding as when somebody acquires an excessive number of items and stores them in a chaotic manner. Whilst hoarded items are often of little to no value, this is not a requirement for a hoarding diagnosis. Which raises the question of how a hoard may differ from a collection.

It is generally accepted that a collection is something that is well-organized and is easily accessible in the event certain items wish to be viewed. On the other hand, a hoard is chaotic and items within it are not easily locatable due to the lack of organisation. A collection may also be set out on display in a particular way, to be enjoyed by the collector, whilst this is not the case for a hoard. Collector's also tend to focus on one area to collect, for example stamps or memorabilia from a film franchise and, whilst it is possible to hoard one type of item, it is common to see a mixture of items within a person's hoard. Commonly hoarded items include free leaflets and newspapers, as well as plastic bags. In other situations people may not hoard items but will instead hoard animals, acquiring and adopting many more animals than they can care for. Whilst this may be done with good intentions, with a person wanting to rescue the animal from a shelter, the situation often deteriorates as more animals are acquired, which leads to many animals that are hoarded being left unwell and under nourished. Data hoarding is also becoming more frequently seen. Whilst data hoarding may not take over the physical location like traditional hoarding, it can be seen as hoarding none the less, with those who suffer being unable to delete no longer required data and online communications.



There appears to be a role for both genetics and the environment

In many cases of hoarding the collection of items take over a person's property, often taking precedent over living conditions. Therefore it is not uncommon for a person to have to adapt their living arrangements due to the size of a hoard. In many cases a person may be relegated to living out of one room in a house, as the other rooms are full of hoarded possessions. This can in turn lead to hygiene problems, with many people unable to use bathing facilities, and safety concerns. In many cases hoards can grow to such a size, and will be stored in such a way, that people are at risk of falling, as well as being at risk of their hoard falling onto them. Hoards are also great fire risks and can limit a person's escape in the event of an emergency.

There are a number of reasons why a person's hoard may expand. In most cases of hoarding there will be an attachment to the possessions and, as such, the thought of disposing of anything becomes anxiety inducing and distressing for the sufferer. There may also be an emotional benefit to someone when they buy the item, such as the thought that the item will make them happy, and so items at home accumulate. For other hoarders, there is the thought that an item will be of use someday, or that it will someday become valuable, and as such should be saved. Some people who hoard may be indecisive about making decisions on the utility of an item and so will decide to keep the item in fear of needing it once it has been discarded. In

more OCD related hoarding, a person may choose to hoard items to prevent harm occurring to others. For example, they may feel that discarded cans pose a threat if they have a sharp edge, and therefore all cans should be saved.

Unfortunately, many people with hoarding will be unaware that they are suffering, and will often refer to their hoard as a collection, especially if they feel the items are of value. This can lead to relationship problems as family members become increasingly stressed with the effects hoarding is having on their lives, especially if they share a home with those who are hoarding.

What causes hoarding?

As is a common theme amongst many mental health problems, the causes of hoarding are not fully understood and as of yet there is no definitive reason why someone may develop hoarding behaviours. As we have mentioned previously, hoarding behaviours can be caused by an underlying mental health condition such as OCD or Schizophrenia, or they may be the result of a physically limiting condition. However, these explanations are not useful when looking at Hoarding Disorder that appears independently of other conditions.

When looking at isolated Hoarding disorder, there is not a consensus on the cause of the behaviours. Whilst some people argue that those with a deprived childhood may develop hoarding, others argue that this is not the case, with more research being needed. What has been found is that there appears to be a role for both genetics and the environment. Twin studies have suggested that 50% of variation seen in hoarding is due to genetic factors, with the other 50% being due to the environment¹. Whilst this does not highlight a key factor or cause, it does show that those who are related to a sufferer of hoarding disorder may be more at risk themselves.

How common is hoarding?

Due to the recent addition of hoarding into the official diagnostic manual, there has been limited research on the prevalence of hoarding disorder. In some cases estimates have used both studies since the recent addition, and studies of the symptoms as part of other disorders previous to the new diagnosis classification. This can lead to some problems with these estimates but it is hoped that over the next few years, as more research comes forward, there will be a clearer picture of the problem. It is also important to keep in mind that, as with most mental health conditions, there is a tendency for people to under report their conditions, and the severity of their conditions. Coupling this with the knowledge that many people with hoarding do not believe they are suffering, and as such will not seek treatment, it is highly likely that any statistics regarding hoarding are likely to be under representative.

Despite the previously mentioned limitations to statistic gathering, there does tend to be some uniformity in the figures that we see in regards to hoarding, with international studies finding that the disorder affects between 2% and 6% of the population². Whilst it is not unheard of to presume this will translate to more local populations, we will highlight some country specific findings here as well. For example, some UK based studies suggest that a prevalence of between 2% and 5% is seen in the UK³, which means there may be over 1.2 million people being affected³. Others have suggested the international mark of between 2% and 6% is more accurate⁴. On the other hand, estimates of 1.5% have been seen in studies using the DSM V criteria⁴. It is plausible however that this figure is more representative of those cases which are thought to be more severe, as estimates put these cases at between 1% and 2%⁵. Staying within the European Union, a German analysis has put the rate of hoarding at 5.8%⁶ and a Netherlands based twin study estimated that the population prevalence was between 2% and 4%⁷. Interestingly they highlighted that, as people age the prevalence increases, with 6% of those over 55 years of age being affected.



Australian researchers have suggested that hoarding may affect 400,000 Australians⁸ which is in line with between 1% and 2% of the population. Others have suggested the number of people is higher and more in line with the international findings, suggesting a rate of between 2% and 6%⁹. Australian research has not only looked at how prevalent the problem is, but there are unfortunately statistics that highlight how hoarding is a dangerous condition, with some suggesting that in the year 2009, 24% of preventable house fires were the result of hoarding⁹. Interestingly, information out of the neighbouring country of Japan has highlighted that this is not simply a western problem. Whilst researchers were looking at hoarding within an OCD setting, they did find many of the characteristics were the same as when the disorder was seen in western sufferers. They also found that over a third of their OCD participants also had compulsive hoarding¹⁰.

Hoarding is also a problem in North America, as it is globally. In Canada for example estimates suggest that between 3% and 6% of the population may be affected¹¹, with others predicting a more conservative 2% to 5%¹²; with it being suggested that over one million Canadians are likely suffering¹². In the USA, estimates have a rather wider range, with some research suggesting that between five and 14 million

Americans may be suffering¹³. This is a surprisingly high number as, when looking at previous research into hoarding within an OCD context, estimates of up to 1.4 million sufferers were suggested¹⁴. When looking at percentage rates in the context of population estimates, one study on college students estimated that 2% to 4% were likely to be suffering¹⁵, whilst estimates of the whole population fell more in line with the international rate of 2% to 6%¹⁶. When looking at the impact hoarding has on the people, it was estimated that in one year in San Francisco, hoarding costs \$6million¹⁷. Importantly this was a study looking at hoarding within OCD, but this still shows how much of an impact hoarding can have.

How is Hoarding treated?

When hoarding occurs within the context of another disorder, treatments for that disorder will likely alleviate the symptoms of hoarding, although specific hoarding treatments may also be utilised. When looking at hoarding as a standalone disorder there are two main approaches to treatment, psychotherapies and medication. The primary medications used in the treatment of hoarding are similar to those used in OCD, which is unsurprising as until 2013 hoarding was mainly diagnosed as part of OCD. These medications are antidepressants that fall into the category of Selective Serotonin Reuptake Inhibitors (SSRIs). For some sufferers these medications have been shown to alleviate symptoms or to help treat the anxiety that often comes with hoarding treatments.

However, the main treatment option for hoarding currently is psychotherapies, specifically Cognitive Behavioural Therapy (CBT). CBT for hoarding looks to help a person understand their hoarding behaviours, such as the reasons why they struggle to discard things, as well as involving behavioural tasks revolving around reducing acquisitions and also discarding objects. This will be done gradually with the support of a therapist and often may involve a professional organiser, but this is not always the case. The goal of treatment is not to have completely cleared a person's hoard by its conclusion. Instead treatment aims to change the way a person thinks about objects and the way they behave so that they can continue to work on their own and with the help of their family, to declutter and reduce their acquisitions. Treatment can also improve the way a sufferer categorises and stores items, so that clutter is not building up for situations where it may be useful.

The treatment for hoarding is a difficult process and can be quite challenging, especially as many sufferers do not believe they have a problem, and as such are not committed to the treatment process. Others may feel shame and embarrassment and so do not seek treatment until later life when the problem is much greater than if treatment was sought early on. However, we do encourage anybody who feels they may be suffering for hoarding to seek treatment as soon as possible to ensure the best possible treatment outcomes so they can get back to a quality of life that they deserve.



What to do if you suspect someone is suffering?

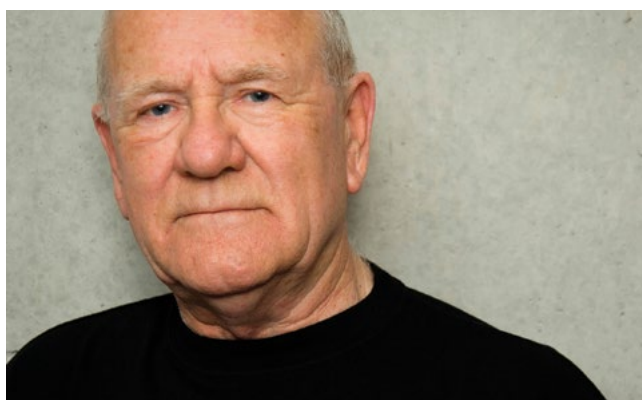
If you do suspect that a relative or a friend is suffering from a hoarding disorder then this can be a very difficult time. Understandably you are going to be concerned for their welfare and the welfare of those around them. It is likely that you will have tried to talk to them about their condition and been met with a denial of a problem. On the surface this can cause a level of anger and upset, as to you the problem is clearly visible. However, it is important to remember that, for many of those who are suffering, they do not see their hoarding behaviours as a problem. It may be as a friend or relative that you need to convince the sufferer you know to seek treatment, or you may need to seek the initial treatment on their behalf. In order to find the best way to do this in your local area, it may be advisable to arrange an appointment with your General Practitioner for yourself to discuss your concerns. In some cases you may need to involve the local social services for the safety of your friend and any potential children who may be living with them. Whilst we do not suggest this as a first course of action, in some cases it is required for the safety of the sufferer. This may feel as though you are betraying your friend but it is important to remember that you will only have done this for their safety and the well-being of their children.

Throughout the process of treatment seeking, if this is required, the sufferer is going to need all the support they can get. Throughout the process, whilst you will become frustrated at times, it is important to avoid being judgemental of the sufferer. It may seem like an easy task to throw things away but it is important to remember that the sufferer is unwell and there are many factors involved in the process. It is also important to be patient. The process of treating hoarding is a long one, that continues long after treatment and so it would be unfair to expect a sufferer to be cured and a property to be cleared in a short time frame.

In fact many properties may never be cleared, but progress will be made and it is important to acknowledge this.

When looking to help ease the impact that hoarding is having on a person you may be tempted to suggest, or even provide, extra storage space. Whilst you may feel this will help, it is likely these areas will simply also become filled with clutter. The same goes for clearing rubbish without permission. Clearing any of the hoard is likely to be extremely anxiety provoking and upsetting, as these items often have an emotional value to the sufferer. If you as a friend or relative simply go in and clear the property, or employ somebody to do this, then this can have an extremely negative impact on the sufferer. This will also lead to trust issues and may end your relationship. In the long run the underlying issues of hoarding will also not be solved and the condition will return, sometimes to an even more extreme condition than before.

It is important to remember that, for many of those who are suffering, they do not see their hoarding behaviours as a problem



If you are providing care or support for somebody suffering from hoarding, or if you are living in the house with somebody who hoards, then this can take a toll on your own mental health. It is important to ensure that you also stay mentally healthy and seek your own care when you feel you need it.



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