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Obsessive-Compulsive Disorder and Related Conditions

In this pack-

Obsessive-Compulsive Disorder

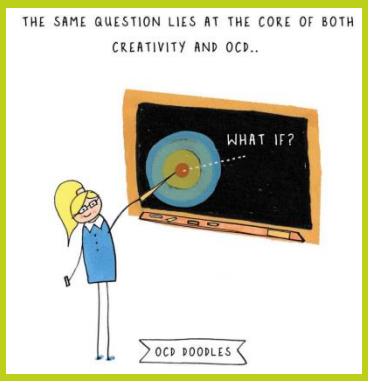
Obsessive-Compulsive Disorder (OCD) is the name given to a recognised condition that causes someone to become stuck in a cycle of distressing obsessions and compulsions. It is a very debilitating and often misunderstood condition, so much so that many hide it for years or decades. In fact, it's much more common than originally thought, and estimates are between 1-2% of the population. The good news is that OCD is a treatable condition, with both therapy and medication available that can help with management and recovery.

Obsessions

Obsessions happen when you become overly preoccupied with intrusive thoughts, misinterpreting them as indicators of risk and responsibility.

Intrusive thoughts are random and automatic worries, images, or sensations that everyone experiences as part of being human. They are the result of the brain constantly scanning for interest or danger, and hold no meaning in themselves. They are hypothetical in nature, so most people describe them with the words "What if…". For someone without OCD, most of them go by without notice, while others might catch someone's attention briefly because of the topic they are about.

If you have OCD, **obsessions** around one or more themes cause you to particularly notice those intrusive thoughts. Through the worry and attention, these random thoughts feel more and more meaningful. What defines an obsession is that you can't let go of your worry until you feel completely sure that it is dealt with. Any uncertainty or doubt around it feels unbearable. Obsessions are always about unwanted or feared things, and might cause you to feel that you are responsible for resolving the issue, preventing harm, or finding the answer.



Intrusive thoughts can be about things the person wants or agrees with (like daydreaming about a random and impossible situation) or against the person's values and desires (like randomly thinking back to an upsetting event).

Obsessions within OCD revolve around **unwanted thoughts**, causing them to become more **frequent** and **intense** through fear and anxiety.

Doubt

A key element of obsessions is that they are driven by doubt, not by lack of rational thinking. People with OCD tend to be aware of the irrationality of their concerns, which for many actually causes even more distress. Although you might know, logically, how unlikely the feared outcome is or that you are not responsible for avoiding it, the smallest possibility that this isn't the case becomes intolerable. When anxiety is triggered by a feared situation, it is so strong and loud that the logic is drowned out, and someone cannot help but carry out compulsions to get relief from it. The solutions then become part of the problem, as compulsions bring more attention to the topic of the obsession and the relief they bring reinforces the cycle.

Obsessions can be about any theme or topic, from something very specific to a general feeling of danger. Some common themes include contamination, violence, sexuality, religious beliefs, past or future events, abstract or existential questions, and relationships. The reality, though, is that every person struggling with OCD will have their own, individual, set of worries based on who they are and what matters to them. The OCD cycle will look the same no matter the theme, and the anxiety it brings will be just as intense and real to the person, because it is doubt rather than a rational fear that drives it all.

Intrusive sensations

While the majority of obsessions revolve around thoughts or worries, intrusive experiences also include images, sounds, and sensations.

Sensations can be particularly confusing or 'sticky' because the human brain is capable of making them feel very real. If you are worried about feeling excited or aroused, this can in itself cause the physical feeling you are looking out for. This doesn't happen because of desire or enjoyment, but can feel like it does because of the real feelings in the body combined with the doubt of OCD. For example, this might cause someone to feel like they want to smile at a 'bad' thought.

Many people who struggle with sexual obsessions find that these can bring intense physical sensations that feel like arousal, which are often referred to as 'groinal responses'. These are different from real arousal because they do not bring enjoyment and are instead a distressing and upsetting thing to experience.

Some people also refer to intrusive 'urges', though it's important to understand that this is different from actually having a desire to do something. It is the fear of that intention that brings on the sensation.

The cycle of obsessions, anxiety, and compulsions is what defines OCD and is shared by every person living with it. Some people, though, also use labels to describe what their OCD looks like. These are not officially different types of OCD, so you won't see them in our informational resources, but you might come across them in other OCD spaces or resources.

Here are some examples of labels based on the theme of the obsessions:

Contamination OCD
HOCD (Homo/Heterosexual or Harm)
Sensorimotor OCD
Existential OCD
POCD (Paedophilia)
ROCD (Relationship or Religious)
False memory OCD
Real-life OCD

Compulsions

Compulsions are purposeful actions that a person with OCD takes part in to get some relief from the anxiety and obsessions they experience.

Like obsessions, these can take any form, and the OCD cycle will be the same no matter what they look like. The actions or rituals most associated with OCD are visible ones, such as checking, cleaning,

hoarding, or arranging things. Most people with OCD, though, also experience mental or invisible compulsions such as:

- Rumination, which is going over and over thoughts, possibly to try to rationalise
- Checking thoughts or memories
- Asking for reassurance from others
- Avoiding situations or people that bring on the intrusive thoughts
- Neutralising, or thinking a good thought to cancel out the bad one
- Avoiding anxiety or compulsions by trying to accept that the thoughts are true

Here are a few examples of labels based on compulsions:

Pure O (mental/invisible compulsions only)
Checking OCD
Staring OCD
Rumination OCD

Compulsions can have a seemingly logical connection to the topic of someone's obsessions, like hiding knives due to a fear of stabbing a loved one. They can also be completely unrelated, though, like wearing matching socks to reduce the likelihood of one's house burning down. It can help to remember that it is doubt and a feeling of responsibility that drives compulsions, not logic. In fact, even if the compulsion seems logical, the person will not stop until they've fulfilled a certain requirement or until it feels 'just right'. This might be several hours into the ritual. No matter how rational or irrational a person's worries or safety behaviours seem, using logic is not going to be a successful way of breaking the cycle.

Previous definitions of OCD included that some people might experience only obsessions or only compulsions. It is now better understood that all people living with OCD experience both, but sometimes in less obvious ways. Someone might perform compulsions that are not directly triggered by intrusive thoughts or obsessions, but this is because of the cycle becoming more automatic in the brain. In these cases, the obsession is no longer a fear of harm, for example, but a fear of the harm-based intrusive thoughts in themselves. Some describe this as 'obsessing about obsessing'. The goal of the compulsions in this case is not to relieve anxiety, but to avoid it coming up at all.

Myth: poor parenting or difficult childhood experiences such as a divorce or bullying cause OCD/anxiety

People with OCD, their families, and their loved ones do no cause OCD. A specific event or set of events might have contributed to how and when the OCD symptoms started, but not to the fact that they did.

The most important thing loved ones can do isn't to worry about whether they're to blame, but rather to support the person with where they are in their journey to better understanding and recovery.

Causes

There has been a lot of research into possible causes of OCD, but there is no definite answer, as it can be different from person to person. Like many mental health conditions, it seems to be a mix of genetic tendency, psychological factors, and experiences.

Genetic – OCD and related symptoms tend to run in families. Family members of people with OCD might have the condition itself, other anxiety-based struggles, or involuntary jerky movements (tics)

Psychological – Individual tendencies like being vulnerable to stress and anxiety, feeling overly responsible, or a sense of perfectionism could be tied into why a person gets so 'stuck' in the OCD cycle

Environmental – The experiences and societal values someone is exposed to in their life can inform assumptions or pressures that become a part of the person's OCD cycle

Triggers

A trigger is the event or experience that brings on the symptoms, rather than the reason

When OCD symptoms arise because of becoming a parent or obsessions revolve around parenthood, this is often called Perinatal, Maternal, or Parental OCD.

OCD Action has an over-the-phone support group open to anyone experiencing Perinatal OCD. See a full list of our groups here.

The charity Maternal OCD offers resources to people struggling with this.

CADAT-PAX (Centre for Anxiety Disorders and Trauma – Parents with AnXiety) is a unit for new parents within the larger CADAT specialist OCD treatment service.

for them. This can be a single traumatic event or, in most cases, the build-up of life stressors eventually 'spilling over'.

Certain life events are known for being common triggers for anxiety-based conditions such as OCD. Becoming a new parent, including the family planning period, usually brings up feelings of responsibility, and is one of the most common triggers for symptoms of OCD starting or getting worse. A new parent might be particularly vulnerable to becoming anxious in response to intrusive thoughts about their parenting or the wellbeing of their child. There might be a hormonal element to this, but it can happen to fathers and adoptive parents, as well. Some people know at least in part what brought on their symptoms, while for others it was mainly a case of bad luck. The good news is that the treatment for OCD is not based on the cause or trigger, so there's no need to know. Rather, it looks at getting you 'unstuck' from the OCD cycle you are currently in through changing your relationship to the thoughts and practicing new reactions to them.

Severity and impact

OCD is a condition that varies greatly from person to person, not only around themes and compulsion styles but also in levels of severity and constancy.

While the impact of OCD ranges from mild to very severe, each person's distress is very real. Everyone experiences obsessions and compulsions on occasion, but for the experience to be labelled 'disorder' (the D in OCD) they have to cause distress and impact noticeably on the person's quality of life.

When someone lives with OCD, they don't experience their worries and rituals as quirks or annoyances, as they might look from the outside. The intensity of the anxiety and doubt that is felt on the inside is debilitating, exhausting, and often constant. The irrationality of the cycle can be scary or confusing. On top of this, it can bring to feeling ashamed and alone, or like you are losing touch with reality when you are not.

It is very common for people living with OCD to keep their symptoms hidden. This can be because of the embarrassment someone feels about their irrational worries and behaviours, and often because of a fear of their intrusive thoughts being misunderstood as desires. Being aware of what is rational and what isn't doesn't help reduce the anxiety or 'stickiness' of the OCD cycle, but it can

allow the person to choose what they show to others. You might stick to invisible compulsions when around other people as much as possible, or have an easier time holding back while you're out, and then get overwhelmed by anxiety and the need for compulsions when you get home. OCD is often referred to as the 'hidden' or 'secret' disorder, and people who struggle with it might wait years, even decades, before seeking any support. This is also in part because of misinformation and misunderstanding about the condition. Someone might be told that there is no help available or that they just need to learn to live with it. In reality, there are reliable and proven treatments available for OCD and recovery is possible.

Whether you think of your OCD as a disability or not, you have legal rights and protections under the Equality Act 2010.

In it, disability is defined as a condition that impacts your ability to carry out day to day tasks for a year or more of your life.

> In 1990, the World Health Organisation listed 'Obsessive-Compulsive Disorders' within the top ten most debilitating health conditions, based on its effect on daily activities, social life, work, and education
>
> In 2008, it was ranked 5th in most disabling mental health conditions

Common myths

Knowledge and understanding about OCD has greatly improved compared with even a few years ago. It is more common for non-specialist professionals to be able to recognise OCD for what it is and offer the right support. Still, it can be helpful to be aware of myths surrounding the condition.

Myth: OCD is rare in children and therefore won't be diagnosed

Fact: OCD can affect children, adolescents, and adults. The NICE guidelines state that the earliest age it can be reliably diagnosed is 4-5 years.

At least half of adults who get help for OCD report having it as children. In most of these cases, they did not tell anyone because they were embarrassed, or they did ask for help but didn't receive it.

You can find more information about assessment of young people on page 31 of the NICE guidelines

Myth: People with OCD just want control

Fact: People with OCD are often deeply distressed by how little they can control what is happening in their mind. Compulsions and rituals do not help them feel more in control, but often less, because they can't stop themselves from taking part in them. They happen because the person feels an overwhelming sense of danger and compulsions give some temporary relief from this.

Myth: People with OCD enjoy their rules and compulsions

Fact: Obsessions revolve around unwanted intrusive thoughts that go against their values, desires, and beliefs. The psychological term for this is 'ego-dystonic'.

The OCD cycle is driven by anxiety and doubt, and could not work as it does if the intrusive thoughts were wanted.

The biggest myth: there is no help for OCD

Fact: There are well-researched treatments available, both privately and through the NHS, which can help you recover from OCD.

There are many misconceptions around OCD and recovery. Some people are told they just have to learn to live with it, others are offered the wrong support. Through our services, OCD Action can support you to access treatment at the right level for you.

You can read more about the recommended treatments – Cognitive Behavioural Therapy with Exposure and Response Prevention, and Anti-Obsessional Medication – in our Treatments for OCD pack.

You can read about how to navigate the NHS system and access support in our Accessing Treatment for OCD pack.

You can also contact our helpline to speak to a volunteer about how to access treatment – on support@ocdaction.org.uk or 0300 636 5478.

Body Dysmorphic Disorder

Body Dysmorphic Disorder (BDD) is the name given to a recognised condition that causes a person to become deeply preoccupied with a perceived fault in their appearance, which causes them to be stuck in a cycle of distressing obsessions and compulsions around the way they look. It is a very debilitating and often misunderstood condition, so much so that many hide it for years or decades. Estimates about how many people live with BDD can vary greatly between 0.7% and over 2%, because even those who reach out for help might feel too ashamed to talk about what they're experiencing. The good news is that BDD is a treatable condition, with both therapy and medication available that can help with management and recovery.

Obsessions

Obsessions in BDD revolve around one or more perceived problems with the way someone looks. This might be something only noticeable to you, something minor and slightly noticeable, or a normal change in appearance like wrinkles or male pattern baldness. What defines the obsessions is that they are excessive and very distressing, causing someone to associate their perceived ugliness with rejection, worthlessness, and hopelessness. An older term for BDD is 'imagined ugliness syndrome', but the term 'imagined' misrepresents the condition, which causes the ugliness and distress to be felt in a very real way. The term 'perceived', which means felt, is more accurate.

Part of the obsessive cycle of BDD are intrusive thoughts about appearance. **Intrusive thoughts** are random and automatic worries, images, or sensations that everyone experiences as part of being human. They are the result of the brain constantly scanning for interest or danger, and hold no meaning in themselves. They are hypothetical in nature, so most people describe them with the words "What if…". To someone without OCD or BDD, most of them go by without notice, while others might catch someone's attention briefly because of the topic they are about. If you struggle with BDD, intrusive thoughts about looks or ugliness, or how people might respond to you because of this, will particularly 'loud', upsetting, and difficult to let go of.

Intrusive experiences in BDD can also include memories of people being critical of your appearance, which will be given centre stage over any memories of compliments. You might also have images flash in your mind of what you worry you look like, in which the perceived faults are more heightened and noticeable, or feel sensations in your body that are caused by and bring more attention to the areas you feel are ugly. **Obsessions** occur because these intrusive thoughts cause both shame and anxiety, which makes it so difficult to dismiss them or move on. Instead, you are likely to pay them more and more attention with time.

The focus of someone's obsessions can be any part of one's body or appearance. The most common areas someone might obsess over are skin, facial features, hair, symmetry, or muscle size. BDD can also cause someone to focus on the way their clothes look or even the appearance of close others (called 'BDD by proxy', which there has not been much research on so far). It is important to remember that the obsessions and concerns are driven by fear of ugliness and catastrophic assumptions about what being ugly would mean, not by vanity. Vanity, which revolves around feeling or wanting to be attractive, is not part of the experience of BDD.

People who struggle with BDD have different levels of awareness about their condition and the nature of their thoughts and worries. Some are aware that they are reacting disproportionately to the 'fault', but are still unable to let go of it, because of the overwhelming fear and shame they feel. On the other end, obsessions in BDD can feel so convincing that they take on a

'delusional quality', meaning the person is convinced of their ugliness. If you are offered reassurance about what you look like, you might notice yourself dismissing this as just something people say to try to make you feel better.

Compulsions

Compulsions are purposeful actions that a person with BDD takes part in to get some relief from the anxiety and shame. These can be avoidance behaviours, in order to prevent these feelings being triggered, or checking and camouflaging compulsions. Taking part in compulsions is a reaction to the unbearable feelings brought on by obsessions, but the solutions then become part of the problem, as compulsions bring more attention to the topic of the obsession and the relief they bring reinforces the cycle.

People with BDD often avoid social situations, knowing that they will feel embarrassment and self-consciousness if they go. You might also avoid looking at mirrors, again in an attempt not to start the obsessive cycle. Through avoidance, though, public situations and visibility become more scary, and someone might become practically homebound because of how overwhelming the idea of being seen becomes.

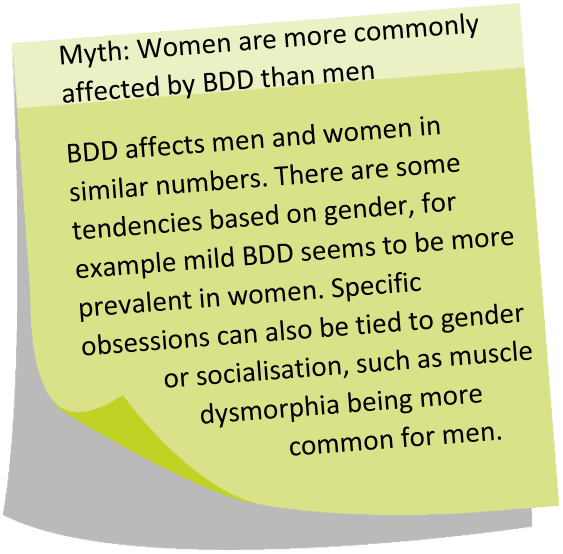
Checking compulsions include repeatedly and uncontrollably looking in the mirror, touching one's skin to feel shape and texture, or asking for reassurance from others about how they look. This can give a sense of 'keeping an eye' on how you might look to others. Like with all other compulsions, this can become more and more engrained with time, making the checking feel increasingly necessary.

Different methods can also used to camouflage or alter appearance. Depending on the person's focus, this might involve using make-up, picking at skin, cutting hair, or wearing clothes with lots of cover. Someone might make repeated visits to professionals such as dermatologists or cosmetic surgeons in an attempt to find a permanent solution to their perceived faults, or even perform cosmetic alterations on themselves. Muscle dysmorphia, in which the person becomes obsessed with muscle size and feels they are too small or 'puny', can bring to use of anabolic steroids, strict diets, or excessive exercise.

Finally, rumination, or overthinking, is a common response to fears of ugliness, and can be a particularly 'sticky' part of the cycle. You might spend a lot of their time and focus asking yourself abstract questions ('Why was I born this way?') or trying to find a hypothetical solution ('If only this part of me looked a little different'). These are an understandable response to the feelings brought on by BDD, but unfortunately only bring more attention and confirmation to the obsessions.

Causes

There has been limited research into BDD and its causes. Like many mental health conditions, it seems to be a mix of genetic tendency, psychological factors, and experiences. BDD most commonly begins in late adolescence, often with milder symptoms in the years before, but can be experienced at any point in life. Small children as young as 5 have been found to display symptoms of it, but it is rare for a diagnosis to be given before the age of 12.



Genetic – BDD and related symptoms tend to run in families. Family members of people with BDD might have the condition itself, other anxiety-based struggles, or depression

Psychological – Individual tendencies like being vulnerable to stress and shame, perfectionism, or a sense of worth that is strongly affected by others' opinions could be tied into why a person gets so 'stuck' in the BDD cycle

Environmental – The experiences and societal values someone is exposed to in their life can inform assumptions or pressures that become a part of the person's BDD symptoms. For example, being teased or bullied about appearance can be a pre-curser and these memories or messages can become part of the person's obsessions, even if their appearance has changed since the teasing happened

Triggers

A trigger is the event or experience that brings on the symptoms. This can be a single traumatic event or, in most cases, the build-up of life stressors eventually 'spilling over'.

Some people know at least in part what brought on their symptoms, while for others it was mainly a case of bad luck. The good news is that the treatment for BDD is not based on the cause or trigger, so there's no need to figure it out. Rather, it looks at getting you 'unstuck' from the BDD cycle you are currently in through changing your relationship to the thoughts and practicing new reactions to them.

Severity and impact

BDD is a condition that varies from person to person, not only around themes and compulsions but also in levels of severity, constancy, and awareness.

While the impact of BDD ranges from mild to very severe, each person's distress is real. Everyone experiences obsessions and compulsions on occasion, but for the experience to be labelled 'disorder' (the D in BDD) they have to cause distress and impact noticeably on your quality of life. Many people are concerned with the way they look and might use the same methods to feel better, but to fall under BDD this must take at least an hour per day of someone's attention, be done in response to a deep distress, and only have a limited effect on the person's ability to engage in day to day life. The ugliness or upset you might feel about the way you look is kept up by fear and shame, so will not go away with the right change in appearance. Rather, specific treatments can help you step back from the cycle at your own pace.

The intensity of the anxiety and shame that are brought on by BDD are debilitating, exhausting, and often constant. Without treatment, it can feel like there is no way out of feeling the way you do about how you look. You might struggle with low moods or depression because of it. It is very important to remember that there is hope, and BDD is a treatable condition that you can recover and get your life back from.

Getting help for BDD

Fact: There are well-researched treatments available, both privately and through the NHS, which can help you recover from BDD.

There are many misconceptions around BDD and recovery. Some people are told they just have to learn to live with it, others are offered the wrong support. Through our services, OCD Action can support you to access treatment at the right level for you.

You can read more about the recommended treatments – Cognitive Behavioural Therapy with Exposure and Response Prevention, and Anti-Obsessional Medication – in our Treatments pack.

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Body-Focused Repetitive Behaviours

Body-Focused Repetitive Behaviours (BFRB) are, as the name implies, repetitive and unwanted actions a person performs on their body as part of an anxious cycle they become stuck in. The most common ones are skin picking and hair pulling, but other behaviours such as nail biting or eating hair can also become compulsive in response to anxiety.

Also known as habit disorders, they can be very debilitating and distressing, and people who struggle with them might hide their condition for years due to embarrassment and lack of understanding. Even though these seem to be very prevalent – around 5% of the population – many professionals are unaware of the conditions and of the fact that there is successful treatment and support available for people struggling with them.

The cycle

The behaviours the person takes part in are different from standard grooming behaviours because of the damage and distress they cause, and because they are part of an automatic loop driven by anxiety. You might experience this in different ways. Some people feel a physical sensation such as a tingling in their fingers or on their skin, which becomes more intense with time and can only be resolved through the behaviour. Others might pick, pull, or bite when they feel anxious. The compulsions can be intentional and ritualised, like picking at bumps in the skin while looking in the mirror, or on the other end of the spectrum can happen without someone noticing. You might only realise you've picked or pulled once you notice visibly, like finding a pile of hair next to you. Most commonly, people tend to use their own fingers, lips, or teeth to perform the behaviour, but items like tweezers can also become a part of it.

While everyone's individual cycle and experience of a BFRB will be different, in all cases the compulsion will be a response to anxiety, bringing a mental and/or physical feeling of relief. The relief or even pleasure you feel causes the brain to view it as a good way of managing anxious feelings, which makes the response quicker and more automatic. The results of the behaviour, though, might then cause more anxiety and upset. Bald patches, damaged skin, and torn nailbeds can be embarrassing in and of themselves, and further to this you might feek ashamed of not being able to stop. You might find yourself avoiding social situations or camouflaging the damage caused, which can increase the pressure and anxiety you feel around the BFRB.

Common responses from loved ones or professionals are to view the behaviours as a bad habit or to only acknowledge the external and visible results. BFRB are complex and treatable conditions that can have a huge effect on someone's quality of life, so should be treated as such. Many people find that the pressure they feel from themselves or others to 'just stop' actually increase their anxiety and can make their condition worse. Like other obsessive-compulsive conditions, the BFRB cycle is driven by trying to manage anxiety. It takes time, patience, and practice to learn a new response, but it is possible with the right support.

Skin picking

Compulsive Skin Picking (CSP) is also referred to as Excoriation or Dermatillomania. People with CSP pick at imperfections, spots, moles, or scabs on their skin to the point of damage. This is most common around the face but can occur anywhere on the body.

If you struggle with CSP you might feel an 'itching' in your fingers or skin that you feel can only be relieved by picking, making the urge too

strong to ignore. Afterward, you might feel frustrated or disappointed because of the physical damage or due to feeling like you've failed to hold back from picking.

For many people who struggle with CSP, the picking is performed in order to achieve a smooth feeling on the skin, sometimes in a perfectionistic way. In this case, the cycle becomes vicious and entrenched because the damage to the skin will then trigger further anxiety and picking.

Hair pulling

Compulsive hair pulling is referred to as Trichotillomania (TTM or 'Trich'). People with TTM will pull at or break their hair in response to anxiety, which can cause visible bald patches or even damage to the skin depending on how the pulling is being done. The most common places to pull from are the head, eyebrows, and eyelashes, but people do pick from anywhere on the body.

If you live with TTM, you might experience a build-up of tension before pulling, which is then relieved by taking part in it. Sometimes the brain's association between pulling hair and anxiety relief might cause you to take part in it when you are not anxious, as a self-soothing behaviour. In any case, the feelings after pulling are often depression, shame, and disappointment because of not being able to hold back or due to the visible effects.

People who struggle with TTM can also develop problems in their wrists due to the repeated movements or gut issues if they also ingest or chew on the hair.

Causes and triggers

There has been limited research into BFRB and their causes. Like many mental health conditions, it seems to be a mix of genetic tendency, psychological factors, and experiences. The behaviours most commonly start in adolescence, but can develop at any stage in life. CSP is more common in women than men. TTM has similar prevalence in girls and boys as children, but from adolescence is more frequent in women.

Genetic – Body-Focused Repetitive Behaviours tend to run in families. Family members of people with a BFRB might struggle with one themselves, or with other anxiety-based struggles

Psychological – Individual tendencies like being vulnerable to stress and anxiety, low self-esteem, or a tendency to respond to emotions with physical action could be tied into why a person gets so 'stuck' in the cycle

Environmental – The experiences and societal values someone is exposed to in their life can inform assumptions or pressures that become a part of the person's symptoms. For example, perfectionism could be part of the reason a person becomes so distressed by the results of their compulsions

Condition vs symptom

These grooming behaviours can also be symptoms of a different condition, such as BDD, processing disorder, or dermatological issue. Knowing what condition is bringing on the symptoms is important, because it will determine the appropriate treatment. For example, the focus of therapy will be different between a person living with CSP and someone who picks because of their BDD.

If you are taking part in repetitive, body-focused behaviours, you should be assessed by a mental health practitioner who has expertise in obsessive-compulsive conditions. The key focus of an assessment should be what the driver of the behaviours is – what brings someone to feel the urge – and how it makes them feel.

Getting help for BFRB

Fact: There are well-researched treatments available, both privately and through the NHS, which can help you recover from BFRB.

There are many misconceptions around recovery. Some people are told they just have to learn to live with it, others are offered the wrong support. Through our services, OCD Action can support you to access treatment at the right level for you.

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South West London and St George's NHS
Mental Health NHS Trust

This booklet was written by Dr Lynne Drummond, Consultant Psychiatrist, Head of OCD/BDD Services, South West London and St George's Mental Health Trust.

A Guide to

Hoarding Disorder



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What is Hoarding Disorder?

People with hoarding usually acquire a large number of items which they then have difficulty in discarding. Many people with problematic hoarding have extreme emotional attachment to these items and find it extremely distressing to contemplate parting with the items. A consequence of severe hoarding is that the individual has so many items that they can no longer use their living space. This can result in problems with health due to difficulties in maintaining hygiene; risk of fire; risk of falling or being crushed by objects and structural damage to the property. In these severe situations, there is often also financial hardship and self-neglect as the individual may pay for storage of items rather than basic self-care.

Although by far the most common type of hoarding disorder features inanimate objects which can be bought, acquired for free or in some cases, stolen, there are also other types of hoarding. Animal hoarding is a little researched distressing problem seen by veterinary surgeons and animal charities when individuals have huge numbers of animals which they often believe they are "rescuing" but, due to the numbers are kept in poor conditions and often suffering or even close to death. Another recent description is data hoarding whereby individuals store huge amounts of electronic data and e-mails which they are extremely reluctant to delete.

Who gets it?

Hoarding can occur as part of another disorder or as a standalone condition. People with Obsessive-Compulsive Disorder frequently also have problems with hoarding.

In general people with hoarding disorder are more likely to live alone; less likely to have been married and more likely to be in middle or old age when they are seen by the psychiatric services. The sex incidence is approximately equal.

"...His house, when eventually cleared, was found to be structurally unsound due to the weight of the papers..."

It has been estimated that as many as 6% of the population of Europe has significant problems with hoarding.

One of the striking features of hoarding is the extreme emotional attachment people feel to these objects which, to the outside world, appear to be a pile of rubbish. The routes of this emotional attachment may often stem from early life. Some people with hoarding disorder give histories of either an emotionally deprived childhood where they formed attachment to objects rather than people or childhoods where money was extremely scarce and no item was wasted. Not everyone who hoards has such a history, however.

Many people have large collections of items. For example some people collect books, CDs or DVDs. The distinguishing feature between whether this is a "collection" or a hoarding problem can be whether these objects are accessible and utilizable. In other words whether or not there is any organisation in the collection. For example, a man was very interested in West End plays. He thus bought 7-8 newspapers a day as he wished to check and then keep the reviews for these plays. However, he found he lacked time to "properly" read these and to check the entire paper and so he kept the entire newspaper. By the time he was seen by mental health services, he had filled his 5 bedroomed house from ceiling to floor and had a small pathway to enable him to access his kitchen, bathroom and sofa. His upstairs was completely inaccessible, his bath was full of papers and all but one ring of his gas cooker was covered with papers. He thus was in a state of extreme self-neglect and was living with constant risk of fire or being injured by falling papers. His house, when eventually cleared, was found to be structurally unsound due to the weight of the papers.

What can be done about it?

It used to be believed that patients who had hoarding responded less favourably to treatment than those without hoarding problems. However, recent research has demonstrated this is not the case and have shown that even with severe hoarding, the prognosis is good if the individual agrees to engage in therapy

There are 2 main approaches to treatment, drug therapy and psychological treatment known as Cognitive Behaviour Therapy (CBT).

Cognitive Behaviour Treatment of hoarding disorder

The most difficult and problematic part of treating hoarding disorder is trying to get the hoarder to accept treatment. Most people with hoarding are intensely ashamed and embarrassed about the way in which they live. They feel desperately inadequate if anyone comes to their home and often live a life of a recluse to avoid such humiliation. In addition to this feeling of inadequacy and guilt, there is also often intense attachment to the horded items.

Anyone who is trying to help a hoarder should be aware that what, on the surface appears to be a pile of rubbish, is often the hoarders most prized possessions. One hoarder described the experience of a family member trying to clear the house as feeling as if they were being raped. It is therefore a slow process to gain the hoarders trust and to help them to discard items. Complete clearance of a home could take a year and is very unlikely to be achieved in a few days or weeks.

It is important to note that this treatment is quite different from pure "decluttering" as the hoarder is taught how to deal with the problem and to gain skills to prevent recurrence. The stages of treatment are:

Gaining trust and a relationship between the hoarder and the therapist.

As already stated this can take a few weeks and cannot be rushed. A patient can feel violated by any heavy handed intrusion.

Obtaining agreement that no further potential hoarded items will be obtained and brought into the house throughout the course of therapy

On occasions where hoarders have their houses cleared against their will, the problem will tend to develop again very quickly as they have not learned how to prevent the new acquisition of items.

Teaching how to discard items

The hoarder needs to experience the fact that the longer they hold onto items, the more difficult it can be to discard. The first decision made quickly is usually the best. It is also advisable to discard items so that they cannot be easily retrieved if the will falters later. Voiding items when the rubbish collection will occur shortly is one good way. However if progress is to be made in a reasonable time, it may be possible to enlist the help of relatives and friends to clear items and take them to the Local Authority Recycling plant on a daily basis.

Examining thoughts associated with the items and ideas of self-worth

Many hoarders have low self-esteem and distorted views of self-worth. Examining the thoughts and emotions with the therapist can be useful if correcting these.

Allowing the hoarder to continue with discarding items

Once the hoarder has seen how to discard items effectively then they usually need time to proceed with this process.

Relapse prevention

The therapist and hoarder need to indentify strategies that will help the hoarder if they find themselves tempted to start hoarding items again.

Drug treatment of hoarding disorder

Almost all of the studies on hoarding disorder have involved patients who also suffer from obsessive-compulsive disorder.

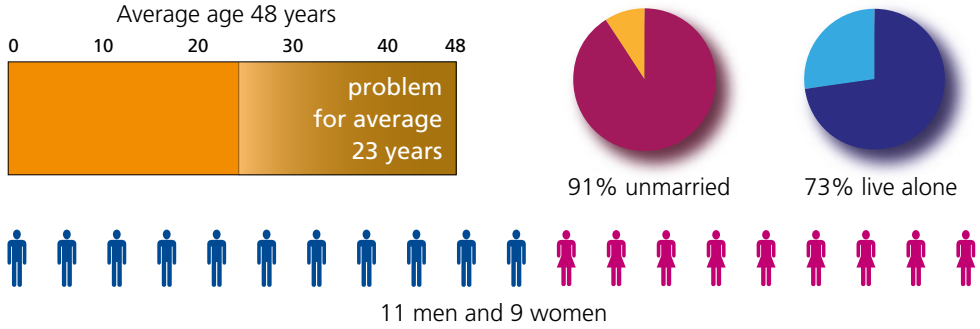
A group of drugs known as serotonin reuptake inhibitors (SRIs) can be useful for people with hoarding. These include clomipramine (a rather old-fashioned drug which some patients prefer) and more modern selective serotonin reuptake inhibitors (SSRIs) with fewer side effects (sertraline; paroxetine; fluvoxamine; fluoxetine; citalopram and escitalopram). The dose of the drug needed to have a beneficial effect is higher than the doses used to treat anxiety and depression. So, for example, a dose of 200mg sertraline is likely to be required as opposed to 100mg which may suffice for depression.

As well as SSRIs, some patients are prescribed dopamine blocking drugs. These drugs are sometimes known as "antipsychotics". However the dose used, in conjunction with the SSRIs, is much lower than that required in the treatment of psychotic disorders and the risk of side-effects is much lower. On their own, these drugs are probably not useful for hoarding but may have a role as an adjunct to the SRIs.

Does treatment work?

Increasingly it is being reported that people with hoarding disorder, if handled sensitively and if willing to address the disorder, can be helped. The studies have involved both drug treatment and the use of Cognitive Behaviour Therapy as described earlier.

In our National Specialist Centre for Obsessive-Compulsive and Body Dysmorphic Disorder, we examined the outcome of 20 hoarders referred to us. The hoarders consisted of 11 men and 9 women. They all had profound problems and had received a long list of previous treatments. They had an average age of 48 years and had had the problem for an average of 23 years. 91% were unmarried and 73% lived alone. After 6 months, they improved by an average 31% on clinical measures.



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