

Trichotillomania

'A Guide for Sufferers'

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What is trichotillomania?

Many people play with their hair; some twiddle it in their fingers whilst others relentlessly search for split ends or even pull out the odd grey hair. This is all fairly common, and pretty much harmless- it's a momentary action and forgotten soon afterwards. However there are some of us who are plagued by hair- beyond just twirling it and feeling it in between our fingertips. We are searching for something, something special that will make everything "right". This something may be a hair that is a different colour, texture or just not where it should be and it MUST NOT exist on our bodies anymore and therefore shall be RIPPED OUT albeit by instrument (tweezers being a common conspirator) or fingers. Problem solved? Well no. Perhaps a little relief was experienced but most likely short lived as something in your head tells you it must continue, it cannot stop, everything is still not alright. It goes on to another hair that has been sought out for its antagonistic qualities, and it too shall be ripped out hopefully with root as to discourage it growing back. And then either the hand or the eye, if a mirror is involved, search for the next intruder that's causing the grief, then another hair, another, and then countless more. Somehow you come out of this little zone, maybe due to an outside disturbances, (the telephone often being a saviour), discomfort, pain or from just seeing the amount of hair piling up on your clothing.

There's a technical term for pulling your hair out compulsively, 'trichotillomania' (often called TTM), and it is a recognized medical condition. Most sufferers feel alone with their condition. They often hide it for many years as they think they are crazy - why is it they can't stop themselves from resisting this urge to rip their own hair out, not only from their scalps, but possibly eyebrows, eyelashes and any other area on their body? The fact that this act was given its technical name over 100 years ago does not always provide comfort to the sufferer, but at least they know that IT IS SOMETHING REAL, not something their brain has inflicted on them alone.

Trichotillomania was a term first used by the French physician Hallopeau in 1889. It is derived from the Greek 'thrix' (hair), 'tillein' (to pull) and 'mania' (madness, frenzy). Although the literal translation concludes that such sufferers are mad, this is far from true. Trichotillomania is a recognized disorder in psychiatry, classified as an Impulse Control Disorder or Habit Disorder. Such a disorder describes one as being unable to resist or control the impulse to do something harmful to oneself. TTM has also been linked to Obsessive Compulsive Disorder (OCD), Body Dysmorphic Disorder (BDD) and Self-Injurious Behavioural Syndrome (SIBS). It is also very common for sufferers of trichotillomania to experience one or more of the 'anxiety disorders', and it often drives depression.

TTM can begin after a stressful or traumatic event, and is thought to be more common in those whose family members already suffer from certain mental illnesses. It is believed to be due to a chemical imbalance in the brain. Many theories exist, there is no definitive answer to what causes it.

Who Gets trichotillomania?

TTM usually begins in early adolescence, around 12 or 13 years of age (though evidence of baby trichs does indeed exist) and is more common in girls than boys. Many teenagers with TTM feel isolated and unable to express themselves to friends, boyfriends, and family members.

Living With TTM

"To tear one's hair out" may seem quite a whimsical saying to some, but to me and many like me it is a constant source of anguish, shame at being found out, and guilt as to why the hell I do it. People often ask me about the bald patches in my hair. A throw away comment usually doesn't suffice, "But why?" they keep asking, "Is it chemotherapy?" The sensible thing would be to ignore their comments, but a little sense of needing to confess the truth prevails, the hope that if they knew the anguish, then maybe some kind of solace will be mine. Of course this very rarely happens. People are curious beings, often judgmental and extremely hurtful. I have a career of nearly eighteen years of compulsive hair pulling with ex friends, numerous workplaces and several countries behind me to attest to this.

Most people are shocked; ask stupid questions like if it hurts to pull my hair out, why do I not just stop and why on earth I do it in the first place. I personally find hairdressers the worst when it comes to subtlety - their shock, then questioning can often be heard over the top of the blow dryer. It starts with them mentioning hair breakage, then asking if I cut my hair myself, and then it comes the judgment as to why I would want to do such a thing to myself. Next there's always a tip how to stop, perhaps a comment regarding lack of will power or sheer madness, then there's the infuriating snide remark to finish off this horrendous public exposure with, "you'd look so much better with long hair."

Yes, the ignorance of strangers, friends, work colleagues, family members and even those in the medical profession can be very irritating. It is no wonder that most of us remain in hiding for as long as we possibly can. Where's the joy in being ridiculed and not being able to explain (even to yourself), why this hair pulling is beyond your control and dominating your life?

Triggers

What makes you start pulling is referred to as a 'trigger'. One major problem is working out what your particular trigger is, and then why it is a trigger, then how on earth you stop it making you pull your hair out. The questions go on, your thoughts race, you become uneasy, possibly panicked and confused as you don't know the answers, and then you end up pulling your hair out because you just don't know what to do; all this tension is building up, you feel it has to be released, your hand goes to your head and it all starts again.

CASE STUDY: A Sufferer's Perspective

'It is like your head is in a vice, a different kind of pressure - it is all building up. Is it physical pain? You don't know, but your head is hurting, swimming even, all this information is going around, you try to sort it but then it winds back upon itself, coming at you trying to grab your attention from different angles. It has got to stop. You want it to stop; but it continues, circling, weaving in and out. What people said, what you think they should have said, what you said, what you should have said, what's going to happen, what you wish would happen.... Yes it is definitely weaving around now, possibly like a big snake, just when you think it has passed, it strikes out and bites you- this sudden pain, is it just mental or do you really feel something. Why won't it all stop? Sort it out logically, calmly. Thoughts - why aren't they in order, why won't they be sorted and STAY sorted? Your hand is at your head ... there's a sense of soothing, but also of pain. You know what the end result will be ... more bald patches and hair on the carpet that the vacuum cleaner just won't pick up. But you just can't control it.' (Anonymous)

"GETTING LOST IN THE ZONE"

Characteristics of TTM

There is little sense of prolonged relief as you've probably just realized that now you are left with not only questions to yourself as to what just happened, but, knowing that YOU did this to yourself and don't really know why and you weren't able to stop yourself. You know it will happen again and then you have to explain the bald patches to curious people as well as having to live with the personal reminder for at least several months until the hair grows back; and live with the knowledge that this is all self inflicted. Often so much time is lost that the day is replaced by more bouts of hair pulling and there is no time left for other activities such as social outings, work or domestics. Studying, talking on the phone, driving and watching television are all moments when you're vulnerable to getting lost in the zone, and once you're in there, there's no telling when you will return to reality. Free time where your brain can just 'lapse' into this vicious cycle, is your enemy.

You Can Find Her Behind The Door

by BrenDakota

**There once was a little girl with eyes full
Of rain. Tears she cried, of self-made pain.
Alone she hunkered in shame, behind a door.**

**Wanting to feel this pain no more.
Hands full of hair, she didn't know why.
The more she pulled, the more she cried.
Her family did not understand the matter.
They thought it was a cry for attention.**

**And that they gave her with so much aggression.
It put the little girl in more of a depression.
The years went by, and the girl grew into a woman.
Still hunkered behind the door.**

**Still wanting to pull no more.
But wait a minute, she is not alone.
There are many whom gather behind the door.
With hands held tight together.**

**We can win this fight
We just have to stick together.**

(www.Trichotillomaniahelp.com)

CASE STUDY: Trichotillomania

Anna was a 27 year old woman who had been pulling out her hair since she was 13. She recalled it began when she found a single white hair and pulled it out. She then developed a 'fascination with the hair root' and felt a sense of 'release' when the hair was pulled. Sporadic, brief episodes of pulling a few hairs a day gradually progressed over years to the point where she would sometimes spend hours pulling her hair each day. She found that it got worse just before she got her menstrual period, or when she was upset or under increased stress at school and at work or when she was worrying about an up-coming event. The hair pulling was a complex and ritualised process where she would search for the right hair, attempting to pull it out by the root. She would spend some time fiddling with the root and then repeat the process. She used tweezers and other implements to pull the root out. Her hair pulling grew worse and she began wearing a bandana to cover the areas of hair loss and then a scarf to cover extensive areas; eventually she wore a wig. Her hair pulling forced her to give up her promising career as an athlete because of an intense fear that her hair pulling would be exposed. It also caused difficulties with social relationships and dating because she was fearful her 'shameful habit' would be exposed.

(from Honigman R, Castle DJ. Body Dysmorphic Disorder: A Guide for People with BDD". MHRI, 2003).

Families and TTM

A girl living with her parents and older siblings began ripping the hair out of her scalp at the age of twelve. After several years of concealing her hair pulling (including hairs and whiskers from the family cat), her family noticed that she was not just playing with her hair twirling it, but actually pulling the hair out of the scalp. Bald patches were becoming apparent on her head. Her mother's reaction was to tell her to stop and do something else with her hands, whereas her father's reaction was to yell at her across the room hoping to embarrass and shame her into stopping. When this failed he resorted to throwing things at her head (particularly "Licorice Allsorts").

Beyond that, her siblings chastised her for wanting to be the centre of attention, ignored the problem or teased her, insisting she was mad. Only after five years of continuous suffering did the girl's mother decide to seek a medical opinion. To this day (18 years later), the family members, apart from the mother, are reluctant to acknowledge there is a problem and show little interest in her current treatment and its effects. One sibling was questioned regarding her thoughts on the subject; her response was that it annoyed her having to vacuum more often!

Family members can be of great support to someone with TTM. Acquiring as much knowledge on the subject is a step in the right direction. Other advice follows (quoted from a sufferer's sibling):

- Don't judge
- Be there (for the sufferer)
- Listen and offer support
- Don't treat the person any differently
- Ignorance of others causes mental anguish, leading to a variety of other issues - low self-esteem, depression and anxiety. This may lead the sufferer to live their life differently to the one that could be.

Relationships and TTM

Relationships are difficult, no matter what your situation is. Secrets are something that we are taught can destroy relationships, but what if a secret is a necessity? Imagine if you are in constant distress, but try to conceal it from those close to you. Perhaps you once expressed this, only to have your confidence shattered by that someone close. Or worse still, such an admission of your difficulties caused them their own distress. So what do you do? You conceal such a thing, hoping that you suffering the pain is better than them knowing and feeling it too. So it is a secret, just a little one, but a secret nonetheless.

This type of concealment can cause great tension between partners as the partner feels something is being hidden from them. Also, a lack of knowledge on the subject can lead to confrontation as the partner does not understand the sheer depth of the problem - often thinking the problem can be solved by their partner exhibiting, 'greater willpower'. Therefore, it is important for loved ones to research and stay informed regarding TTM. Numerous websites have outreach information and support for not only the sufferer but their beloveds (see "Resources").

Seeking Treatment

Seeking treatment for trichotillomania can be extremely difficult. Most people don't even know that chronic hair pulling is a medical condition that has a diagnostic label. From the onset trichotillomania often goes unnoticed or is believed to be just a phase or 'habit' that will be grown out of. General medical practitioners are often not well enough informed to offer any consolation or advice to a sufferer. Sometimes a doctor's ignorance can prevent someone from seeking further advice especially if the problem is belittled with responses of, 'just stop' or 'wear gloves'. Current research has revealed that TTM is more common than first thought. The Internet is a fantastic source of information with not only medical explanations and helpful advice but support groups for sufferers.

Library research is also a valuable tool with a number of books recently being published on the subject. If such resources are not available to you and you are still having trouble receiving medical treatment, it is best to contact a mental health centre. A very reassuring fact is that trichotillomania is listed in good medical dictionaries available at health clinics.

Medications

Medications do not really have a great track record in the treatment of TTM, though some people do find medications such as the serotonin antidepressant drug (SRIs - serotonin reuptake inhibitors) can reduce the urge to pull. Certainly these medications are useful if you also have depression, OCD, or BDD. The modern "selective" SRIs (SSRIs, such as paroxetine, citalopram, escitalopram, sertraline, fluvoxamine, and fluoxetine) are generally well tolerated in terms of side effects, and can be taken safely in the longer term; they are not addictive, but symptoms can recur if they are ceased, especially if this is done too rapidly.

Possible Strategies

The most important advice to be given regarding trichotillomania or any other disorder is to seek help. It is very isolating realizing that you suffer from such a condition as it is certainly not particularly media friendly. But do know this: if you keep concealing the problem, it will eat away at you. Precious time will be lost by hiding the problem, your existence may become totally consumed by the fear of discovery - you may cut yourself off from those close to you or even prevent yourself from having further relationships.

Careers and goals for the future can be affected as instead of concentrating on what you could do with your life, you are too busy worried about the idea of being discovered. Please know that although it is very hard in initially seeking help and a continuous battle once you know TTM is treatable, your life will be more open to living if you do find the strength to fight.

Possible Strategies (cont.)

Each case of Trichotillomania differs as sufferers live in various environments and have different triggers, therefore making set treatment too exclusive. However, there are several ways of finding relief no matter what the situation. Habit Reversal is a technique whereby you try to “prevent” yourself from hair-pulling by doing something with your hands that is simply incompatible with pulling. For example, when feeling the urge to pull you can clench your fists and put your arms outstretched; or simply sit on your hands. Other things that can help prevent hair pulling include cutting your nails short so you can’t “grip” your hair, or using hair products that make your hair slippery. In desperation, some people even find simply shaving their hair is better than incessant pulling and having to live with the inevitable bald patches showing. This idea has several positive aspects. Firstly the hair is too short to pull with fingers (you must throw those tweezers away!) and secondly it means that hours are not spent in preparation to go outside. Rather than worry about whether bald patches are concealed and how to hide them you must be brave and just go! It does take time for the hair to grow back evenly and initially people may comment, but the relief of being able to leave the house immediately without any preparation is immense.

If you have longish hair one of the best ways to prevent unconscious pulling is to tie the hair back quite firmly, fixed into position with some serious styling product. This is quite helpful in the way that the hair is so stiff that individual hairs are difficult to separate and it gives you more time to realise what you are doing and consciously make a decision as to whether you want to continue pulling your hair out. Another strategy is to put bandaids on your “pulling fingers”.

Dietary Strategies

Research is presently investigating the effect that diet has on the urge to pull hair. It has been reported that scalp and body pullers are food sensitive and initial relief can be found by avoiding sugar and caffeine. Further research has found that many hair and body products also contain chemicals that act in a similar way to those within the “bad” foods. The fastest rewards can be found by avoiding sugar and caffeine, but unfortunately it may take up to 30 or 40 days of abstinence for the body to rid itself fully of the bad effects.

Several foods can often counteract the ‘bad’ ones including garlic, most acidic fruits, dry red wine and unsweetened yoghurt. Skin creams and hair care products also contain ingredients that may cause irritation. One of the most common ingredients to be avoided is stearyl alcohol.

Other chemicals and foods that have been found to counteract the bad reactions are listed in the John Kender diet. John Kender is a Professor from Columbia University who has tested the diet theory on not only himself, but also hundreds of others with trichotillomania (www.trichotillomaniahelp.com/JK/jkdiet.html)

Internet Resources

The internet is a great source of relief for sufferers of trichotillomania. By entering a search engine it is possible to find an amazing array of information on a condition once deemed ‘rare’. Other benefits of the internet include discovering that you are not alone, that help is available and that not only support groups exist, but if you are a little shy you can anonymously use noticeboards and chat rooms with other sufferers. By realizing that you are not alone it is often easier to gain the confidence to seek help.

www.trichotillomaniahelp.com

www.trichotillomania.net

www.trichotillomania.co.uk

www.trich.org

www.trichotillomania.info

What I Have Found Helpful **by Catherine Phillips**

I hope these thoughts will be of some benefit to people with TTM and their families. My advice would be to seek counseling and don't give up on the medical profession if at first you don't succeed. I personally had to challenge many medical practitioners just to have them realise I was not mad. Eventually I was referred for appropriate treatment.

You should surround yourself with positive people, take care of your body and indulge yourself with massage - especially scalp. If confronted by ignorant people in your everyday life asking too many questions, I have found the best response to be, 'it's a long story' or to simply turn the questions back on them 'goodness, don't you ask a lot of questions?'

As for hairdressers or any others it is best to remind them that they are meant to be professional and their lack of knowledge is regarded as ignorance. Saying that if they expect you to reward their rudeness and misguided curiosity regarding a situation that is obviously very delicate with a response or payment is clearly unthinkable - often hits the spot.

Self preservation is the answer.

Best of luck,

Catherine

Further Reading

Castle, D.J., Phillips, K.A. (2002): "Disorders of Body Image", Wrightson Biomedical Publishing, UK

Honigman R, Castle DJ (2007): "Living with your Looks", University of Western Australia Press

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