

Trichotillomania and Me

By Carmel Pardy



I can't really remember when I started pulling my eyelashes out but I know that when I first began to do it,(primary school age) it was just something I discovered I could do. I liked the feel of it and I liked the way I could make my eyelid click as I did it. So excited about my discovery, I even showed my brother what I could do and even tried to pull my brother's eyelashes out. I can still remember the moment, the two of us standing together in the bathroom trying to do it to one another. When I reflect on this I do believe that this was just innocent childhood exploration. But then I crossed the line. I can't remember when or how but new that pulling my eyelashes had become something more sinister. I knew that it was no longer something I should share with anyone and indeed something that I now had to lie about when asked, "what happened to your eyes". (Anyone with trichotillomania will know the excruciating feeling when someone confronts you with your darkest secret).

People with trichotillomania will tell you that for a long time they thought they were the only person in the world with such an affliction. You really do believe this and so as a result internalize this, that is, I believed there was something really wrong with me and that I was just no good. When it is said that trichotillomania is the compulsion to pull out one's hair, it is just as important to acknowledge the secrecy of the condition. People with tricho are vigilant at maintaining their secret. I believe this component of the condition is just as important to treat, it's important to unravel this secret. I think it's just as important to tackle this, if not more important than just focusing on the act of pulling .

Often people with tricho will feel embarrassed that it is such a bizarre behaviour, however I've now observed people without tricho pull the odd hair out and

have watched them complete the same ritual that a person with tricho would. This tells me that the act of pulling is not so bizarre and normal in a way. However when you cross the line and pull your hair so much that you cause damage and it impacts on your whole life as it did mine.....it really is a serious matter. And it's the intensity of the pulling and the absolute intensity of the urges and the secrecy surrounding this condition that is bizarre. Pulling out my eyelashes impacted on my whole life. It shaped the person I was and how I presented to the world, I was effected by it when I was pulling and it was present even in the moments I wasn't pulling. That is, I got through the day with the knowledge that I would have relief by night, pulling my eyelashes out.

When I decided to share my personal story, I asked myself what I really wanted people to know and understand about trichotillomania. I kind of thought it's easy as someone without tricho to read about it and then say, "oh that's that thing where you just pull your hair out" as if it's something a person does casually without thinking. So what's important to me is to try and really capture what it is like for someone with trichotillomania. I want to describe to you, if I can, what life with tricho was really like for me.

Pulling my eyelashes out was the way I started the day and the way I ended the day for many years, probably 30 years. When I was a child I can remember being curled up in bed hiding under the blankets just pulling my eyelashes out in chunks. Then I became more refined with my pulling, pulling one eyelash out at a time. By the time I was fifteen I had no eyelashes and by the time I was in HSC I had no eyelashes and ridiculous half eyebrows. I mainly pulled at nighttime. The damage was very obvious but I was very alone with this situation. I received no help, in fact no one in my family discussed it. No one told me to stop doing it and no one reached out to me either. I left home at 18 and my pulling advanced, pulling whenever I had the opportunity, morning, during the day and night. I could spend hours in a 24 hour period pulling. Sometimes I couldn't get out of bed because I had to keep pulling or I couldn't go to sleep at night because I had to pull. If I fell asleep and woke up in the middle of the night I would pull then too. It was very exhausting and I feel very sad about how consumed I have

been by this condition. Sometimes it would take me days to get one particular eyelash. It would be so small but I could feel it, and I'd want it out. The intensity of this kind of urge was crippling. I could spend many sessions on one eyelash. Can you imagine that, I would have to contort my head in a peculiar way or pull my eyelid so tightly and press my fingers together so hard to get it out.. Sometimes in these moments the intensity was so great, that I feared my eye might fall out, or that I would have a heart attack.....at times like this, I fantasized about being locked away and being restrained to a bed, so that I could no longer do it. One time I even got up out of bed and drove to an all night chemist to buy some tweezers to help me in my mission. I sneaked out of the house whilst my partner slept in bed ,bought the tweezers went home pulled the eyelash out and then hopped back into bed. And then I would carry on the next day as if life was normal. In one of these intense sessions of pulling I did so much damage that my eye swelled up and bled. I could not go to work. I lay in bed depressed and lonely and listened to the ABC, it happened to be this same week, OCD and anxiety week in about 1994 and they were talking about OCD and happened to mention trichotillomania. I couldn't believe it. That was my first moment of realizing there must be others. It was not longer after that, that I read a chapter on tricho in a book about OCD. From that day I just stopped pulling. I probably went 100 days without pulling. I had a lapse in the middle of this and pulled two eyelashes. I thought I was cured!! This was an exciting time for me and I met others with tricho at a support group and I even shared my story the following year at this same conference.

I guess I would say that this was the beginning of my recovery but my journey since then has been a long one. For the next 16 years I continued by battle with trichotillomania. Those one hundred days were the longest period I had of not pulling until now. In that period between then and now I muddled along. I have been in and out of therapy for years. I made the decision not to ever use medication for trichotillomania because I really understood that the act of pulling out my eyelashes was something I did to myself, it wasn't something that just happened to me. It was a direct affront on myself, that I did. I went through CBT with psychiatrists and psychologists at different times. The most useful thing I

got from this was learning how much I loathed myself, I had no self-esteem, and little confidence or belief in myself, despite the fact that I was very competent in many areas of my life. Yet my inner self was in turmoil and had been for a very long time. I also realized from doing CBT that I was in a constant state of ambivalence and making the smallest decision caused me angst. I was competent in a crisis but experienced everyday sort of anxiety all the time. On the outside I appeared to be functioning but my inner world was horrible. Having tricho is like living a double life.

For much of this time I guess I just quietly battled on. I focused on general self awareness and tried to develop an understanding of my relationship with my trichotillomania. My tricho has been both friend and foe. I've been very defeated by it at many times and then had times of acceptance which has also been useful. In these times of trying to accept it, I'd not focus on stopping the pulling and would just think this is a part of me and acknowledge that it's had a purpose in my life. It got me through a volatile childhood, university degrees, being in unsavory relationships, becoming a mother and it provided me with the only way, I knew of getting some peace.

It sounds strange but I guess that's what I haven't gone into yet, how can such a destructive behaviour provide one with peace. When I was pulling my eyelashes out it was like I went into this bubble. I was unreachable when I was pulling. I had a need to create this bubble around me. I think it was kind of like, if I hurt myself no one else could or if others inflicted pain on me it would not penetrate and it stopped me from being completely present. So it was like a shield, my protector. The consequence of this was that, that bubble remained to an extent not only whilst pulling but generally. It effected the way I related to people, I couldn't be completely present and completely intimate even with those I loved most. For much of my life my trichotillomania has kept me in a very solo place in the world. Not even those I love most could penetrate that bubble because I have been vigilant with maintaining the secrecy and intricacies of my trichotillomania even from my partner of nearly twenty years that I love dearly and from my precious children. An example of the extent I would go to is, when I would put my

children to bed, I would often stay with them until they fell asleep (I've done this because of my fear that they may develop tricho and I've never wanted them to feel as alone as I did in a dark room pulling out my eyelashes). When they'd fall asleep, I would stay in their rooms just pulling my eyelashes out. This meant that when I came out of their room I could never just join my partner on the couch I would have to sneak past him and go into the bathroom and reapply eyeliner to disguise the damage. I would then rejoin him on the couch as if everything was ok. You cannot have true intimacy when you live a double life like this.

More recently I have lived with the fear of being discovered by my children and I dreaded having to explain it to them. My children were getting to the point when on a couple of occasions they noticed my eyes and pointed out to me that I had hardly had any eyelashes. I can't explain how devastating and frightening that was for me, that my little girls would be exposed to this demon in my life. I could no longer be relaxed with my children and sadly I could not have intimate moments of lying with them, just looking into their eyes, I kind of pushed them away for fear of being found out and because I wanted to protect them. I knew I had to do something.

Another jolting moment I had, was when I was alone in my bedroom pulling out my eyelashes and one of my babies was crying, really crying. I could not go to her. I did not know whether she was hurt, whether she was safe....I just had to keep pulling. I was in that bubble and not even my baby's cry could penetrate it. This frightened me and I realized how much trichotillomania controlled me. My world of tricho was impacting on others, and this saddened me.

I think it was the accumulation of all that I have told you that led me to finally say, no more. I was tired. Pulling out my eyelashes had consumed so much of me for so many years. I just then had this moment where I knew my life had to change. I could not go on like this anymore. At this point of my journey I sometimes had pull free days, sometimes weeks, yet even this was not enough. I had this conviction that I wanted it to stop completely, I no longer wanted to manage it, I wanted to live my life more fully and I wanted to live my life true to

myself. I made the commitment to myself then, that my life would change. I didn't know how, but I knew, that that was what needed to happen. To do this, I knew I needed to believe in myself.

So, I decided to run a marathon. I didn't know if I could do this but I knew I could do it, if I believed in myself. I had to unravel the mystery of the marathon. Running has been very useful to me in my journey. It's simply one foot in front of the other. Breathing in and breathing out. The pain and suffering of running is to me like the pain and suffering of life.....you just experience it and you get through it. Running has enabled me to be in my mind and body, connecting the two. And it has taught me to be very in the moment and present, something that tricho has not enabled me to do. I cried a lot through my training, visualizing myself crossing the finish line. I had a mantra I often said and that was, "when you cross the line carm, your life will change forever". I remained committed to this. I crossed the finish line and knew, that I could believe in myself. People said to me, how do you run 42.k and I quietly new that endurance wasn't a problem for me, I mean pulling your eyelashes out for 30 years, that's what I call endurance.

I didn't stop pulling straight away but remained committed to my mission. I had made an appointment with a new therapist prior to the marathon and started therapy shortly after. As a result of having tricho, I have found it hard to have authentic relationships and new that I had to learn to trust the person I was going to see and in some ways develop an attachment to her, one that provided me with the security to really delve into the depths that I have not wanted to go. I believe that this relationship has been crucial to my healing. I knew this time if I was really going to rid my life of trichotillomania, I really had to talk about 'it' and I knew I had to entrust my vulnerability in another human, the therapist....something I was not accustomed to doing. I had to face my trichotillomania head on. It was no longer useful to count how many days I stopped pulling or to try and will myself to stop pulling. I didn't even think about doing this. Really what I have done is to try and unravel the secrecy of the tricho and have explored what is beneath that, sharing the real me with another

human. When I made the commitment to rid my life of tricho, I knew that I wanted to start living a life that is true to me. So what I unraveled was a lot of pain and sadness that I have not been able to face and my tricho indeed kept me at a distance from this. This has been incredibly painful, to sit with one's sadness and to sit with life's disappointments but has been what I have needed to do and what I have been avoiding for so long. My therapist enabled me to go into the space/ the bubble that I go into when I pull but of course without pulling, this was a cathartic experience. I am now in my ninth month of not pulling. I have no urges at all which is just extraordinary, as any person with tricho would know and I believe the capacity to sit with my pain has enabled me to stop. It has almost been an organic process. I haven't had to resist urges as such, I just stopped. But it has taken a long time to get to this. I sometimes have the sensation of my eyelashes being pulled out. This probably happens daily and is sometimes horrible and makes me feel sick, but I guess this is some sort of trauma or result that I may have to live with as a result of inflicting so much trauma upon myself. This part of my journey, and I'm only in the early stages of it, has been so hard emotionally and there have been times when I thought it was much easier when I pulled. I guess I had this fantasy that when I stopped my life would be bliss and quietly it is, but I'm not shouting with excitement. I think I'm recovering from the exhaustion of living my life with such a debilitating all consuming condition.

Although I feel tired, I do feel a sense of relief. I'm scared sometimes, because I'm aware that I could start pulling again and that would devastate me, to return to that life frightens me. But for now I'm free. I can wake up in the morning and lie peacefully, comfortable in my own skin, I can look my girls in the eyes and love them as they deserve to be loved without feeling like I'm going to be found out and that I'm not good enough for them. I have moments now, many where I realize I'm just being, I'm in the moment and I'm alright. I no longer have to hide and I can have an honest and intimate relationship with my partner, my soulmate. And I can just be in the world now, content at being ME.

Thank you for listening to my story. I hope that it may give other sufferers the courage to continue their difficult journey towards recovery, I hope that it may

give family and friends of sufferers insight into the pain that your loved one feels and I hope that it may encourage professionals to look beyond the behaviour and to really see the person you are working with. Thankyou for this opportunity.