DEAR ALOPECIA

Curated By Chynna Webley

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PREFACE

Penning something so personal can be a very scary thing. I've been toying with the idea about writing about my alopecia for the longest time now, but every time I open up a blank document my mind becomes empty. It's not there isn't much to say, but rather that there is too much to say. The impact that alopecia has made on my life has been such a significant one and it makes me wonder every day who I would be if I didn't have it? Has my alopecia shaped who I am today or rather that and external factors? I've always believed that we are products of our environment, and I'd like to believe that I would be just as socially aware as I am today, but who knows?

I was diagnosed with alopecia at the age of 7. I didn't have a clue how it would affect me until I got older and more self-conscious. Don't you wish that sometimes that you could go back to the days where you weren't as self-aware? In this day and age of social media it can get be very easy to sink into a rabbit hole of pretty faces, perfect bodies, full-bodied hair and wonder to yourself why that can't be you. There have been many a time this has happened to me.

Writing has always helped with letting out a lot of the negative feelings I have associated with alopecia, and whilst I still harbour some of them, the temporary relief I feel once I've typed everything out is nice. I wish it was like that all the time. Which is why I've decided to curate this book of letters which also includes my alopecia journey. I wanted to loop in other people's stories because despite us all having alopecia, not everyone's story is the same. I always think it's important to hear other people's perspectives because there is always a story that someone can relate to.

My exact feelings about my alopecia are convoluted. It's been a long road to get to where I am today and I honestly wouldn't be here if it weren't for my family, friends or the alopecian community I found on Instagram. As a writer, I feel like this idea should have come to me a long time ago but I guess good ideas take time.

I'm releasing this eBook for free because I just want everyone to hear our stories. No, I want everyone to hear us shout about our stories from the rooftops and be loud, proud and happy with how far we have come. Any donations are welcome to either Alopecia UK or the charity in your respective country.

I just want to reiterate something I wrote on my blog, which is: we got this. It may not get any easier (let’s not lie), but if we’ve got the support and the care and the love, then we can do this. We absolutely can.

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AMORITA JONES

Dear Alopecia,

I was once a fluffy dark-haired infant, and then a toddler with lush pigtails and hair ties that matched my outfits.

I was sassy, with the heart of Nala the Lion.

But there are only pictures to prove this to me that this young girl was me. You see, in my earliest memories, you were already in the picture. You were there on the days when half of my curls were in the wastebasket, the other half still clinging to my scalp, not quite ready to let go yet. You were there for the days of makeshift head-wraps, made with bandanas in an array of colors, a different one picked out every morning to match my outfit for school. You refused to be ignored; and then one day I decided the time was right for the world to meet you, officially.

No more hiding, no more secrets, no more fear when taking off a pullover sweater, no more shame of being different. That was the day we finally felt the warm rays of the sun crown us, and the delicate kisses of the breeze on our head, giving us its blessing.

Yet, we have not always been #Bald&Beautiful or #Bald&Brave, as we post online have we?

Oh no, in fact on some days were more like *bald and belittled* or *bald and bypassed, or even bald and barely making it through the day.*

Alopecia, do you remember when we were 4 years; we used to always play at the park in the neighborhood with Akshay? He was a little boy that was our age and we were best friends at the time. We did everything together. One day we were playing in the sandbox with Akshay, and three boys approached us and asked him to play with them. Naturally we went to join them together, but they didn't mean us, they just meant Akshay. Not quite understanding just yet, we persisted to join them. In frustration, one boy came right up to me and knocked my hat off my head.

Exposing me to the world.

He might as well have just kicked me in the ribs. The boys had initially gasped at the sight of me, analyzing me like a mythical creature whose disguise had been snatched away. That quickly transformed into howls of laughter.

See, at this time we had patches of hair still, some longer than others, peeking from under my hat giving the illusion of more. But if we're being honest, you were winning that battle, so I had more scalp to show for than hair those days. I remember the feeling of my eyes burning with the tears I was holding back, I remember the tightness in my throat, as if like the air was barely filling my lungs. Suddenly Akshay's warrior cry broke onto the scene and before I knew it our mothers were scooping us up out of the sandbox. When school started, we saw less and less of Akshay, until one day we went to visit him at his house, and I learned his family was moving. So, you and I said goodbye to Akshay, our first best friend.

Upon starting Kindergarten, I begged my mother for us to find something else I could wear to school, I was terrified that my hats were no longer enough against what school could hurtle at me. This started the bandana era for us. Do you remember how HARD it was to tie those bandanas alone? We spent so long in bathrooms trying to figure it out at school. Every shift of the fabric on my skin sent a shock of panic through me. Panic that somehow, I would again be exposed to my new world, and then have to wait for my mother to come for me.

Do you remember 2nd grade, when so many kids at school had lice, they had to administer a whole day for lice checking in the auditorium? Yeah, well you better, because it was awful. Every kid in school was gathered there waiting to have their scalps inspected like the monkeys on NATGEO we would watch on Saturday mornings. I kept thinking to myself, "What am I going to do all day while people get their hair checked?". I kept wishing my mom would just come to get me sooner since I would do nothing but sit around all day. At least I could sit with her instead of this sea of semi-familiar faces if they called her. A kid tapping me on the shoulder to let me know it was now my turn pulled me out of this thought, I responded "I'm not getting checked, you can go first," and so they did and I went to the back of the room in efforts to not get in the way. As I got settled an adult with white medical gloves approached me letting me know that ALL students will get checked today with no exceptions. I insisted that there was no need for me to get checked because I couldn't possibly have lice. See, you had won the battle and I now had nothing but scalp under my purple bandana, but this woman would not have it. We argued back and forth and eventually the panic took over and I burst into tears begging her to believe me, to trust me, but she refused. Unknown to me, a girl I had become close with managed to slip away from the room to find our teacher. My teacher exchanged words with her out of earshot and then we were walking to the office together to call my mom. After that, I became the girl who cried to get out the lice check.

Remember we did Simon Says exercises? Remember the first time we had to "play with our hair", cause Simon said? Well, wasn't that awkward? Feeling frozen in time, avoiding eye contact with anyone in the circle as my empty fingers hung by my side waiting for the next order. Ugh, and remember the kid who reminded us of Shaggy from Scooby Doo, he would always run up and rip my bandana off when he got a chance. So eventually I started tying them as tight as I could and holding the edges between my fingertips when he was around. Grade school felt rough didn't it? My 2nd grade teacher helped me learn how to put on rubber swim caps when our class started swim lessons at the local recreation center. I was the only girl who changed inside the bathroom stall of the locker room, and I was always the last one out when changing. I love the water but hated what it took for me to be able to swim.

By 4th and 5th grade, nobody "like liked me," and something in my gut told me it was because of you. I was smart, I was funny, I got along well with the boys and the girls, I was never afraid to play and try new things, but there was always something that kept me at a distance. I knew that something had to be you.

Middle school was a nightmare.

I was always the best friend, but never the crush, never on someone's "Top List", never the topic of a "Crush Gossip" session, never the person someone blushed about when picked to get married to when playing M.A.S.H.

All my friends had girl/boyfriends and I had girl/boy-friends.

Alopecia, why did you make me "pretty" but not "pretty enough"?

By now other girls were making snarky comments about "how nice it must be" or how "I didn't know how easy it must be not needing to shave" and "how lucky I was,". But it was I who thought they were lucky. I was constantly mistaken for a boy. Strangers would always tell my mother what a pretty boy I was and asked my sister how much older her brother is.

Their words felt like flames, warm at first but quick to leave a burn.

There even came a time when you started slamming a wedge between my sister and I. Remember that?

Her thick luscious curls refused to be tamed, they are beautiful and free. Though this caused her a great deal of pain and I could give no proper support during evenings spent in tears while getting her hair done. I could see the anguish in her eyes and it broke my heart. I wondered if she felt like an outcast for her hair the same way I did for the absence of my own. I would've suffered right there with her if it meant we got to go through it. And sometimes I wondered if she hated me for not enduring the same as she did. I yearned for us to be able to brush our hair while watching cartoons on Saturday mornings or to braid each other's hair like I saw other girls do.

But you kept us from having that.

Instead you kept us apart as I hid around the corner watching as she got her hair braided.

We hoped high school would be different, but it wasn’t.

Boys now reached for my bandana, demanding I let them see what I was hiding. They questioned if I could really be a girl, if I had no hair. They asked me questions like, “Does the upstairs match the downstairs?”.

We got ***direct*** confirmation that it was you all along.

In freshman year, my best friend wanted to cut her hair and shave a side. Her boyfriend immediately objected, declaring that a girl shouldn’t have less hair than her boyfriend. At that point I wondered if there was any hope for me at all in dating someone at school.

And then I had my first boyfriend.

He thought we were beautiful, and no one had ever used that word to describe us before. It was as if someone was cleaning our foggy window and we were seeing the sun for the first time. He was the boy everyone wanted and somehow, he was choosing me.

We couldn’t let this slip away.

What if he is the only one there will ever be? What if no one else was going to look at me and see ME and not just you Alopecia.

But he was a wolf in sheep’s clothing, and it was that very thought, that made us stay for so many years, wasn’t it? We endured the abuse because, well, how could we go back to the drought after finally tasting the rain? How could we give up the only thing we knew?

Remember that dream of his? Oh yeah, I bet you do.

He and I are together. I was in a radiant dress and “I looked beautiful”. There was that word again… making me feel like I fell out of a dream. But he was saving “the best detail for last,” so we gripped the phone that night, waiting for the typing bubbles to reveal the final detail. When it arrived, it was a dagger twisting in my heart. The finishing touch was his description of long black waves of hair, flowing over my shoulders. It was like this that I was “even **more** beautiful with hair” and “the girl of his dreams”.

“I wish you could’ve seen how beautiful you looked with hair.”

As if I had not already pictured it myself a thousand times over.

Imagining what it would be like to run my fingers through it.

Would they catch in my curls?

What would the texture feel like?

How would it look in a ponytail?

How sassy is my hair flip?

Or to have begged my parents to let me dye it like everyone else was doing.

Or to have someone tuck a loose strand behind my ear like all the telenovelas and romance novels talk about.

My heart was shattered at the thought of what would never be. Yet there you were Alopecia - relentless and never absent from my side. It is only now that I realize so many years later how you may have impacted my self-esteem which in turn impacted the choices I made, i.e. staying with an abusive relationship for 5 years because I didn’t think I could do better than him.

But we got through it! We learned SO much together, and little did we know, a sweet spot was heading our way.

Seeing kindness in people's hearts gave me courage.

While there have been folks who were cruel, ill-mannered or ignorant, there has also been so much light. Remember our best friends in high school? They have loved us for who we truly are. They cared nothing for what anyone ever had to say about us, and they made us feel beautiful even when his words rang hollow and his actions pushed salt in our wounds. It was these bonds of sisterhood that gave me the courage to share you with everyone.

In high school, our medical assisting course assigned a project to present on a disease or condition, so I chose you. I thought by embracing you and telling my class about you, I could eliminate questions about you and evaporate awkwardness.

And it was amazing.

My teachers, friends, and classmates were in awe. I was applauded and praised for my courage. For the first time, I felt **proud to have Alopecia**, and proud that you chose me. Shortly after the bullying stopped but I was still constantly anxious. I needed the security of the bandana, while I told everyone about you, I wasn't ready to ***show*** everyone. I wore my bandanas EVERYWHERE.

At school

After school

During gym class

When my family had company over

To go to the store

I even wore it when I was intimate with my partner.

Nothing could get me to uncover you for the world. Nothing, until prom. I spent hours looking at dresses online, the girls looked like royalty in their glamorous dresses and their makeup was flawless. I wanted prom to be perfect! But there was no place for my bandana in my perfect picture. The possibility of showing you to the world was terrifying, and I was dreading the thought of that being my only option. Yet as the days counted down, you mocked me in the mirror as I tried to envision my bald scalp in an evening gown. When the day came, we stood tall, with the mindset of "Fake it 'til you make it" to keep us going - we weren't going to turn back now. I told myself college HAD to be different. I couldn't continue living my life in constant fear of "discovery" always hiding you from everyone when you were a part of who I am. I accepted that doing anything else would be denying us from truly living life. And so, feeling like Cinderella, each step we took in our sparkling silver heels, was a step closer into our new life starting with prom night.

Everyone LOVED you.

People wanted pictures and I embraced it, I wanted them to remember us, the real us. I promised that from that day forward, I would never hide you again from the world. So, the next day I threw away all my bandanas and never looked back. I used this momentum to keep pushing forward. We even tried modeling, remember? We did a few shoots to build our portfolio and posted them on Instagram to see how they would be received.

We were on fire.

I wanted nothing more than for everyone to see you now. I wanted people who had never heard of you to see you in all your glowing glory. I wanted those who had the same ache in their heart to know they could find comfort in knowing, they were not alone as I had felt for so long. Except now we would make it through those dark nights, together.

Alopecia, you opened a door to a community of beautiful people and I am so proud to be a part of it. I have to be honest, Alopecia, we don’t have the best relationship, but you have given me so much to celebrate and be grateful for. My closest friends are the truest ones. And our crush from high school, the one who said my name right on the first try? And the one who saw you by accident that day. Well we stayed friends all these years and I’m happy to tell you we have been together for 4 1/2 years and living together for 2 years.

Alopecia, you have taught me so much.

You taught me how powerful empathy is.

You taught me to be strong, especially when I feel unwanted.

You taught me to build confidence in who I am, not what I have.

You taught me that beauty comes in any and every form; you just have to open your eyes and heart.

You taught me that confidence is the sexist thing you can ever wear.

You also helped me learn how empowering it is to choose to be vulnerable with someone who loves me, for me.

You showed me just how far, “fake it ‘til you make it,” can get you.

You have helped make me into who I am today. I hope that you will continue to be unapologetic and always present in my life. I know the best is yet to come, we still have so much more to grow, and so much more love to give in this life.

I can’t wait to see how I continue to transform with you by my side. I promise to actively love you every day more than I did yesterday.

With all my love,

Amorita Jones

(Connect with me on Instagram @amorlinda__ or at www.thrivingova.com)

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ANNE

Dear Alopecia,

A baby was born, a little girl with lots of hair. It was something that would catch your attention immediately, beautiful thick brown hair. The little girl grew and so did her hair. Sometimes, when she would wake-up, the hair would be bigger than the girl herself. Together with her blue eyes, her brown hair was one of the first things somebody would notice about her, it was for a fact one of the seven beauty signs. In the booklets her friends would write in, a lot of them would always mention her stunning hair. It became a huge part of her identity and something that she adored.

Then, when the girl was 14, she got alopecia. A hair condition that makes your hair fall out; little did the girl know what was in store for her…

That girl? Yep that is me. I look back at old pictures of myself and I am flabbergasted how beautiful my hair was from the moment I was born. I took it for granted when I had it. When I was 14, which is now 4 years ago, I lost my hair due to the hair condition alopecia. I honestly never thought it would come this far, I just assumed it would grow back. However, as you might have noticed, it did not.

It was a tough time. When my doctor first told me about my alopecia, I had him repeat it 3 times and write it down, as I just could not remember the name. It was something I had never heard of nor seen before. It was scary seeing your hair fall out in clumps. I tried treatments, but at the end I was afraid it would do me more harm than losing my hair would do to me. So, I decided to stop any treatments and to just wait and see where alopecia would bring me. It brought me to the point I shaved off my remaining hair at the end of 2016.

In the meantime, I had already told my classmates about my hair loss, but they kind of forgot about it. When I still had some hair on my head, I decided I did not want to it hide anymore and, so I went to school without covering my bald spots. People were shocked and they thought I was sick. However, after some time, they got used to it and so did I. I must say, it was the start of something great.

In 2018 I decided I wanted to share my story and help others with alopecia. When I first got it, I felt incredibly alone. I wanted others to feel like they are not alone in their hair loss journey. That is when AlopecianGirlboss was born. One of my best decisions ever made, as I met amazing people through my Instagram and blog! Being able to share my stories felt amazing, it still feels amazing. I am a proud baldie and I love to go out with and without my wigs. I am proud of my alopecia and I am also thankful for it, as it has made me the person I am today. I cannot imagine what my life would be like without it and to be quite honest, I don't even want to know.

Before, I was incredibly insecure. Alopecia made me see that I am good as I am and that I do not have to be ashamed of anything. I am good as I am, and I do not need to change that. I started to embrace who I am as a person, rather than trying to be somebody I am not, just to fit in. I truly believe I changed for the better.

Please don't feel ashamed about your hair loss, lots of people go through the same thing as you, even though you might not realise that yet. We are all here for you, one big community coming together to help you through the hard times.

And yes, there are hard times. Times where you look back and think why did it have to happen to me, times where you look back and hope that one day your hair will be back to its old self, or even a better version. Those hard times are tough. There are times I am afraid to go out bald, times I feel unsure about my wigs, times where I wish it was all just easier.

Having hair loss is, because of whatever reason, is not easy. People have a hard time understanding what you are going through and at the same time it is incredibly hard for those standing on the side lines, not knowing how to help you. Communication is the key here. They don't know what to do either, so help them out a little as well. My parents were struggling, but as I made them clear what I was comfortable with and with I was not, it got more clearer to them every day.

Hair loss is a constant journey, one day you feel good about it and other days you don’t. It is hard for us man and woman, to feel comfortable enough to go outside. It is still a taboo; it is something we have to break through together. We can do this.

I noticed that, because I am so open about my hair loss, people on the “outside” feel more comfortable to talk to me about it. Everyone around me who knows about it, also looks at hair loss differently. For my friends, wigs are just normal day stuff. They don’t look up when I take off my hair. They think about the different causes of hair loss, because they now know which causes there are; they are educated.

Together, as a hair loss community working with the non-hair loss community, we can normalise hair loss. So that the 14-year-old me would not have felt alone when she first started her long hair loss journey.

If that 14-year-old girl could have looked in the future, to see where she stands now as an 18-year-old, she would have been proud. She would have known it was going to be okay in the end. It might take a while, but there is light at the end of the tunnel.

I now proudly stand here, together with the hair loss community, to say to you; you got this. The road may be long and hard, but we are here for you, every step of the way.

I love being bald, I love what alopecia created me to be and I am proud of how far I have gotten. I cannot wait to see what the future will bring for me and you.

Love always,

Anne

(@AlopecianGirlBoss)

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CHYNNA WEBLEY

Dear Alopecia,

I always wonder if I should be raging and screaming at you.

Whether I should be kicking up a storm and be angry at whoever caused me to have no hair?

I’m writing this letter to let out feelings I have swirling in my brain and honestly - there are a lot of them. It's hard to get down into words how I feel sometimes.

My journey starts at the age of just 7 years old. I vaguely remember having hair at that age, but I'm an old woman now and my memory is not as it used to be. I do have memories of my mother braiding my hair and lacing ribbons through it on special occasions. There is one particularly hilarious story including bangs, but we won't get into that. It was nice being able to have my long hair brushed and prepped. One memory, in particular, sticks out: it is of me sitting between a family friend's legs on the floor of my grandma's house and getting my hair cornrowed for the first time. It was a beautiful feeling. Suddenly, and quite quickly, that feeling disappeared.

If you ask me to pinpoint exactly when my hair started falling out, I wouldn't be able to tell you. Just as I wouldn't be able to tell you what caused it. I didn't understand what was happening at the time or why I was in hospital so much. The doctors had wanted to put me on steroids, but my mother point-blank refused because steroids are harsh especially for such a young person. I was lucky enough for my hair to grow back at one point, but then at the age of 9, it happened again.

My alopecia journey has been so up and down, and I don't even know how to put it into words sometimes. I have always struggled with my hair (for obvious reasons, you're probably thinking) but the past few years have been the hardest. 3 years ago, I was in the worst state I have ever been in terms of my alopecia. I was still hanging to the last few strands of my hair. I would wake up most mornings and feel sick to my stomach. Crying a lot is very draining, let me tell you that. Calling in sick to work and lying about having an eye infection? That was me. Putting on a brave face and meeting up with friends, all the while wanting to be at home and in bed and away from the entire world? That was also me. No one tells you the emotional impact that alopecia can have on you. It's not easy.

It was 2017 and I was still holding onto the last patches of my hair. It was such a weird time because I was wearing wigs full time at this point, so there was no point in still hanging on. But... it was emotional. To let go of the last few strands? It reminded me of the times when I still had a full head of hair and could do all sort of styles. I was clutching onto memories but I realised I just had to let go. And I did. Granted, I still haven't been out the house without my wig (except to take out the bins, ha) but we move. Baby steps, right?

I'm going to do a little flashback. During my time at secondary school, I had a full head of hair. I wish I had appreciated it more back then and I wish I had taken more care of it. I didn't have to hide under silly hats and bandanas as I did in primary school. I had the option to style my hair the way I pleased and not have to worry about bald patches. The only thing that bothered me was the teenage acne that made my face look like a football pitch.

There was this one time in Science class and I heard, "Hahaha, Chynna has a bald spot" and I panicked. Panic is a recurring theme when it comes to my alopecia. I quickly tried to cover it up. How could I explain it? I had never openly spoken about my alopecia before - my family knew about it, as did my best friend and one of my oldest friends. I just remember I couldn't move for a split-second, my face was burning with embarrassment and I could feel the tears threatening to spill out. Then, a hand gripped my shoulder and firmly took me out of the classroom and I broke down. She allowed me to cry like an absolute baby, but she understood.

After that, no one said anything and I carried on with things.

This lasted up until university. My hair started to get thinner and I panicked (everyday panic, clearly). I knew that stress could be a cause of alopecia, but at the time I didn't link them together. So, I bought my first set of clip in hair extensions and thought, this will do. It got to a point where I had to rely on them every day, and in hindsight, I definitely should not have used them as much as I did because it caused an unnecessary strain on my hair. Clipping and unclipping, pulling at my hair. It's not that I didn't notice. It was more like I didn't care because it temporarily fixed the problem. My patches weren't showing and my hair was even (one side always grew faster than the other, so despite haircuts to even it out, it would eventually just go back to what it was before).

During my first year of university, I still had most of my hair, with barely any patches. When I was 18, my boyfriend at the time asked me about it and I refused to talk about it. It was emotionally scarring for me - to go from a full head of hair to suddenly having patches again. There was one particular incident where one of our housemates asked me about my patches in front of my boyfriend. That feeling of wanting to puke instantly came up. It may have been an innocent question, but a little sensitivity would have been nice, no? I did eventually tell my boyfriend about my condition and was met with nothing but support. Yet, a forced confession did not sit right with me.

When I finished university and moved back home, I was still using hair extensions but it wasn't as bad anymore. I felt like I could breathe a sigh of relief. Yet, that was short-lived. I got my first job and got into a serious relationship. After internships that didn't pan out and dating turning into nothing serious, I felt like this was it. What it was, I wasn't sure, but it felt like the start of something. This is where it began to get rough for me. When alopecia truly took a toll on me mentally and physically. I'm telling, you stress not only affects your mind but it also affects your body.

This serious relationship, I believe, is the reason my hair started falling out again and this time it wasn't growing back. I don't want to go too much into this relationship because he doesn't deserve any of my words, but the worst part of it all is that he turned around and used my alopecia against me. Imagine being told, "Hopefully the next man won’t be repulsed by your bald patches as much as I was."? With something as personal as alopecia, to open up about it to somebody you love is a big deal.

I can laugh about what he said now because he was a ridiculous, small-minded person and even at the time it happened I laughed because if I didn’t then I would have cried. Yet, there are some fleeting moments where I think back to what he said and I get really, really sad. My rational mind tells me that I will find someone who will love me with or without hair, but my insecurities sometimes shout at me and I just want to curl up into a ball and just cry and think I will be alone forever because who wants a bald girlfriend?

Navigating the dating space with alopecia is scary. I find it easy to tell people about the fact that I have no hair nowadays. That part has become a lot easier over time. But then to get close to someone... That's a whole other minefield. When I get to a certain level of intimacy, it takes a lot for me to take my wig off in front of you. I can count on my hand the number of people who have seen me without my wig in real life.

Do you ever get that feeling where you want to puke rather than tell someone how you're feeling? I was like that for the longest time. Especially when it came to dating. I used to find it hard in the beginning when I first started properly dating when it came to my alopecia. How do you smoothly bring up the fact that you don't have hair? There always was this fear in my heart that the person would instinctively react with an, "Ew" and bail. It's a lot easier now, because I can just whack it in my dating profile and link my Instagram so they can already see what I look like with no hair. Nevertheless, it still fills me with trepidation when I start talking about my alopecia.

I am definitely in a much better headspace than I was in 2017. Yes, I have the odd day when I think, “Wow, I got dealt some crap cards” but for the most part, I know that I can rock a bald head if I were to go outside without my wig. I am glad social media exists because growing up I didn’t know anyone who had alopecia so it was a lonely space for a while. My friends and family are there for support, but sometimes it’s just nice to have someone who you can relate to.

I’ve never really wanted alopecia to define who I am. It’s a big part of me, but it’s not all of me, right? Sometimes, despite love and support and the community, a tiny part of me doesn't want it. It is ungrateful, I know, but there are points where I just want a life that is not filled with negative emotions because of not having hair. But we have to take what we got and roll with the punches.

September 2019 was a fun ride and is what started all the idea of this eBook. Connecting with fellow alopecians has been so heartwarming and knowing that I am not alone in the situation has helped me out so much. To my fellow alopecians – we got this. Don’t be afraid to be who you are and always take care of yourself because things like this can be such a mental strain. To friends and family of people who have alopecia: be there for them, support them and love them.

Love always,

Chynna

(@chynnawebley)

4

DEVON CARROW

Dear Alopecia,

You and I have got a whole lot of history. You've been by my side through my high school graduation, prom, first date, the first day of college, and even on my wedding day. I can honestly say you have been with me through thick and thin, the good days, the bad days, the ups and the downs. To be completely truthful, when I first met you, I resented you. Deeply.

You were my worst nightmare wrapped up and placed in front of me during one of the most stressful periods of my life. My dad had a stroke and my grandpa just passed away. I was honestly in a spiral of grief and confusion and you came along like icing on that horrible cake. Let's just say that wasn't the best way for us to start our relationship. However, little by little, we warmed up to each other.

You taught me so much, dear Alopecia, you really have. You taught me to become humbler, you taught me how to stand up for myself, you even taught me how to love myself, more than I ever thought possible. With you, I grew up. With you, I matured, more than I ever would have without you.

Now, here I am, twenty-five years old. We met NINE years ago. I am no longer a scared, trembling, sixteen-year-old girl terrified to walk into school every day. I am now a young woman, married, employed, studying for my Master's Degree. I am now a published author, a guest speaker, an owner of an organization, all because of YOU. Simply, you.

So, I guess the saying "blessing in disguise" really does mean something. You are my blessing in disguise, Alopecia. While not everything about you is amazing, even today, I am truly grateful for you. Here I am now, my dad alive and well, my mom, husband, sister, grandparents, family, friends surrounding me and loving me, even with you near. I am alive and I am better because of you. I will continue sharing our story and I hope that I will one day tell my children about you, how you made me into a better person, and with the stories I tell, I hope they learn the valuable lessons you have taught me.

Yours truly,

Devon

(@thelovespreader | @devon_lucille)

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ELOUISE JOHNSON

Dear Alopecia

I hated you once. Every look into the mirror, every bit of wind that blew, every stare reminded me of your presence. Other-ness consumed me like a fire. My life was spent denying you. I was alone in my hair loss. I was bitter. I was the last person to think that one day we would be friends.

Time wore on.

My negativity waned and waxed with your coming and going. Until one day you stayed. My newly shaved head brought freedom I had not felt before. A weight had been lifted. The bonds of unrequited hope were gone. I had no idea the thing I had been holding onto for so long would bring relief once gone. The fight was over and acceptance came. Alopecia, I would not be who I am without you. Perspective whacked me in the face because of you. Opportunities in life arose because of you. My life has changed completely because of you.

Thank you, Alopecia. I love you.

Ellie

(@topknotchhairsolutions)

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FARAH MOHIDIN

Dear Alopecia,

Where do I start?

We met when I was just an innocent little girl. I had no idea the journey you were about to take me on for the years to come. I had no idea how hard you were going to make my life growing into an adult. You didn't just take my hair away from me, you took away my confidence, my identity, my femininity.

As a child you made me feel so alone. You made me feel like there was something wrong with me. I thought I was bullied because no one liked me. I didn't understand what I had done to make people so horrible to me. But it was all because of you, because you made me look different and they didn't like that. You made my school experience horrible. So I hate you for taking that away from me. I hate you for making me feel ugly. I hate you for taking away something that I loved so much, and for putting me through such a difficult and confusing time.

Why can't you be simple? Why can't you just be something so simple that the doctors can find out why you even exist and stop you? You take so much away from people. Doing it to little children is just cruel.

I have always felt guilty for getting upset about you, because others have it worse. You aren't killing me. But I have learnt I need to let myself be upset, so I can move on from the feelings and become stronger.

You make me feel really low about myself some days. It almost feels like waves of grief, for the hair that you stole and for the life I could have had without you.

But as I get older and grow, those low days become less and less. As I get older my thoughts aren't constantly consumed with worrying about if anyone could see you, like they were as a teenager. As I get older I feel like it might not be so bad having you in my life. There are some days you still make me feel really really awful, but as I grow older, those days become less and less.

I would stop you if I could. But through taking my hair and leaving me bald, you also gave me a lot I wouldn't have had without you.

From having you I gained strength. I gained opportunities I wouldn't have had without you, I gained the chance to help others by sharing my experience with having you.

Without you I wouldn't be using my jewellery making talent to help others with their own insecurities.

Without you I wouldn't have been involved in this amazing worldwide community of people who have you too, and made so many friends which I wouldn't have done without you.

Without you I would have the chore of shaving my legs... and I have felt my sisters leg stubble. So I'm thankful I have you there.

But most importantly without you I wouldn't be me. So I thank you for choosing to be in my life.

From,

Farah

(@farahmlondon)

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JASMINE SUTTON

Dear Alopecia

If it weren't for your unpredictable and capricious (not easy to pronounce) and anything but easy to live with medical condition Alopecia (a noncontagious disease that causes your hair to fall out) I wouldn't be here writing this letter.

Alopecia took the best of me at the young age of 10 years old. Alopecia took my long dark brown hair, my happiness, and what I thought at the time, my beauty. It fell out rapidly, leaving bald patches all around the hair line and I didn’t know why it was happening.

I thought something was wrong with me, until the doctors told me it was Alopecia Areata. My mom and I immediately asked if there were a cure, however the doctor said they don’t what the cause is either.

Hopelessly, I was desperate to find a cure and did everything anything to regrow my hair. The doctor recommended steroid injections which was the most painful treatment I encountered that involved injection several injections into one patch. I ended up bringing a metal spoon to bite on to relive the agonizing pain, while squeezing my mom’s hand. It hurt so bad that I didn’t want to continue the treatment.

I simply hid the patches in the front of my hair line with a bandana every day for the next 5 years until I was introduced to wigs in high school, which I habitually wore from sunrise to sunset for another 10 years. When I was about 23 years old, I lost all my hair on my head and my entire body and hit rock bottom.

I did not feel pretty without my wigs and I became a different person because of the way I was thinking about myself. I thought that I would never be able to live without my hair and that my hair is what defined me.

Most days I lived my life in the future hoping every day that my hair would grow back. Some days I lived my life in the past dwelling about all the horrible memories I had that involved my alopecia and people that gossiped about me or teased me for being “weird looking.”

It was hard for me to focus on the present and live in the moment because I didn’t genuinely love myself and couldn’t see me pass my Alopecia when I looked in the mirror.

Saying that alopecia took a toll on my life is an understatement.

I don’t think words will ever describe how much I let alopecia consume me physically, psychologically, and spiritually. I was depressed and fed up of feeling miserable about myself.

In 2016, I decided to embrace my Alopecia by not wearing my wig to school my senior year in college. I wasn’t scared… I was terrified! I had friends who had no idea that I had alopecia and asked me if shaved my head for a cause. Some thought I had cancer or was sick, and some friends just smiled and said, "Rock that head, girl!". Not everyone gave me that weird “Oh shit, she’s bald” stare. I just kept my head up and focused on the moment instead of overthinking about what other people were thinking. I had to train my mind to ignore people that were staring at me and stop giving attention to people that had negative comments or statements to say.

Instead I focused on the beauty in everything and gave attention to people who smiled and had nice comments to say. From that moment on, I changed my environment and included only positivity in my life.

I began to heal in every way possible.

I practiced yoga, meditated, found peace from within and spoke to people that could relate. I began to follow people that looked like me on social media, and I became inspired by so many beautiful souls that went through similar experiences like dreading windy days and what to do with your hair when you’re going to go swimming with a group of friends.

They inspire me to be just me, and no one else. I wouldn’t be here if it weren't for the people that I saw who were living their best life with Alopecia, loving themselves unconditionally and unapologetically.

Now I can see clarity; I can see my true beauty and beyond. I can love myself and let other people love me like I never thought I could ever be loved. If it wasn’t for Alopecia, I wouldn’t have grown into the person that I am today.

Because of Alopecia, I can speak about my struggles and sorrows and hope that my experience will inspire people living with similar conditions.

We’ve all got something: a medical crisis to face, aging parents to care for, heartbreak in all its many forms. However, we’ve also got something to give: hope, encouragement, a life-saving transplant, or a spirit-saving embrace.

What I’ve learned is that, it’s all about faith, family, and friends. And finding out that you are stronger -much stronger - than you think.

Just Be You; no one else in this universe is like you. So just be you and that’s all you must do, don’t worry about what other people are thinking, because you do not have control over what other people think about you.

See yourself through your eyes and no one else.

Love Always,

Jasmine Sutton

(@smoooth_jazzz)

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LUCY BROWN

Dear Alopecia

Would I be the person I am today without you?

The simple answer is no. You have taught me so much and made me a stronger person, you might have taken away my hair, but I am thankful for other things you have given me in return.

I used to always focus on the negatives of alopecia but over time I've learnt to slowly accept it and try and focus on the positives - for one it makes you a WAY stronger person. You are beautiful with or without hair.

My alopecia story first started at the age of 15, around 6 years ago now in 2014. Running my fingers through my then, long and thick brunette locks in a class at school, I halted as I suddenly felt a small bald patch at the back left-hand side of my head. As soon as I got home from school that day, I looked in the mirror and the reflection confirmed to me that a circular bald patch was apparent. It was very small, no bigger than a 5 pence piece.

Little did I know what a journey I had just started!

At this early stage, I didn't really think that much of a bald patch on my head. It was something at the back of my mind. In all honesty, I tried to avoid thinking about it. I was a busy teenage girl who was very social and loved spending time with my friends and family. However, in the weeks to come this balding patch at the left-hand side of my head had begun to increase in size.

I didn't really want to consider myself facing 'hair loss' at the age of 15. After all, hair loss is not something you consider experiencing as a teenager. I tried not to think anything more of it nor do anything about it; I feel like I had subconsciously convinced myself that it was fairly common.

After Christmas and entering the new year, I noticed that my hair loss was worsening. At a swift rate too. My main concern was the worrying volume of hair falling out as I brushed it or in the shower as I was washing it. By this point, I had also unfortunately noticed that multiple further patches were also beginning to form on my scalp. Although others hadn't realised, running my hands through my hair, I could unquestionably detect a reduction in the thickness of my locks. My hair felt thin and limp and styling it how I used to had become impossible. Anyone who has (or is) experiencing Alopecia will understand how tiring and upsetting it is trying to constantly hide growing bald patches.

It was at this point that I found myself sadly realising that my experience of hair loss was going to affect me more than I had initially thought.

I can still vividly remember standing in front of my mirror, after a shower with drenched hair and wrapped in a towel. I stood in shock as dense handfuls of hair followed my hairbrush as I retrieved it from my scalp. Thick strands, falling to the floor. It felt so wrong that this was happening to me! Every time I would comb through, bundles of strands would fall away. I think this was the first point where I couldn't help but let myself cry!

Following this point and noticing the formation of other smaller patches, in early February I phoned the doctors and booked an appointment. The first doctor I saw gave me a selection of various creams and shampoos, initially suggesting that my bald patches were a cause of a problematic scalp. I held high hope the creams/shampoos prescribed by my doctor would miraculously help regrow my hair!

However, to cut a long story short, the shampoo did not help and neither did the creams. Sadly, the patches were continuing to worsen - slowly but surely. The gradual process of my hair loss felt extremely difficult and draining. It was deteriorating over a period of months which prolonged the confusion and anger I was experiencing.

'Why me?' I would repeatedly find myself thinking. Finding clumps of hair on my pillow as I woke up or on the shower floor whilst I washed my hair, was, to simply put it, devastating and heart-breaking for a 15-year-old girl.

After being diagnosed with Alopecia Areata, I was sent to the dermatology clinic at my local hospital where a dermatologist put me on a course of steroids named Prednisolone. These steroids work with immunosuppressive effects which aim to stop/ slow down my own body from attacking my own hair follicles! I held high hopes that this course of steroids would stop my immune system from attacking my own hair follicles, and they did… however only for a short period of time when my steroid dosage was at its highest.

At first, I saw great results. For the first 4 - 5 weeks things were looking great as 'fluffy' light hairs had begun to grow upon my bald patches. Yet as soon as my dosage decreased, my hair fall began to worsen again.

From December 2015 until March 2016 (when I lost all my hair) it was a downwards spiral, unfortunately.

In later April, I lost all my hair on my head and then a couple of months after this, my alopecia totalis turned into alopecia universalis, which is complete hair loss of the whole body. This period of my life was pretty shocking, and I honestly didn't recognise my reflection in the mirror.

However, in a certain way it also felt like a huge relief. For so long I had been fighting with this draining battle against me. The journey felt so prolonged and heart-breaking for me and those around me.

It has been a long journey, but I feel like I have now reached my most content point. When you lose something like your hair, you realise how much you took it for granted before. Therefore, I now appreciate my wig every day! Alopecia has been a battle, and it still is, however things have got easier. Slowly but surely. Accepting alopecia will never be an overnight thing, but it slowly grows over time and it has definitely made me a stronger person.

It was a secret I kept for 4 years and I learnt a lot from it, one of which that I shouldn't have been afraid or ashamed to share my story. Everyone is facing their own problems (big or small) and people are way more supportive than you could ever imagine.

When my hair first started falling out, I felt so ashamed of my own body for what it was doing to me. I was afraid to tell others because of what they might have thought of me… but over time my thought processes regarding this have massively changed. I began to accept my alopecia and consequently became much happier within myself. I can honestly say that things do get better. Don’t get me wrong I can still have down days and struggles but with acceptance comes more happy days than sad.

It took me time, and I am still learning to accept my alopecia, but I truly feel that happiness within yourself starts when you begin to accept and love yourself the way you are.

Happiness truly is the strongest beauty.

Love always,

Lucy

(@myalopeciajourney)

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SHEREE GOLDSMITH

Dear Alopecia,

Who would I be if it wasn’t for you?

Quite simply I wouldn’t be me. You don’t define me and you no longer consume me. However, I now feel an incredible sense of relief that I feel almost proud to be able to say your part of me. But it’s not always been that way...

Shame?

Shame was the perfect word to describe how I felt when I found that first patch, 3 or 4 years ago. ''Who do I tell? What will they think? What's wrong with me? Why me?''

Relief?

The relief when it all grew back a year or so later! I felt like ''I'd defied the odds and made the impossible, possible!''

Heartbreak?

The heartbreak when I found another the second time around. ''This can't be happening!''

Despair?

Despair when the whole lot fell out along with my lashes and brows within a month of finding that patch. ''I will never look pretty again''

An emotional rollercoaster is the perfect summary of Alopecia. Name an emotion - us Alopecians, you bet we've felt it. I'm not ashamed to admit I've been through an absolute turmoil with my emotions.

I used to call you A, it was easier for me at first, I'd get choked on the word Alopecia and A I hope you realise what you took from me. But I hope you also know that in the end, you gave me so much more than you took. You are the definition of uncertainty - the deepest and most destructive kind.

The most important lesson you taught me and made me believe was that true beauty goes deeper than the surface. The realisation set in, how much personality and heart actually define a person, and the way we look is only the shell. You taught me to work on myself, to better myself but most importantly to be myself. Being myself meant showing myself, showing myself to the world in the vulnerable state I considered myself. So I made my Instagram page, this is where I found community and I found my happiness again. I told the world and the world supported me.

You have created so many beautiful humans! Both physically and emotionally. The kindest souls I have ever met have been at the hands of this suffering you present. I have to thank you for that.

Very early on I found this quote: ‘Let your heart define you, not your hair’ and I chose to let that be the case for me. Whatever life throws at us, we have a choice. We channel any amount of strength no matter how small, and we use it to adapt and overcome the situation or we let it consume and destroy us. At first, we do, and that’s okay, that’s the kind of impact you have on us. We all get there in the end somehow, everyone’s journey is as unique as their soul. The one thing that makes us so beautifully different and no one can take away, not even you. The most important part of us.

That’s all I’ve ever really wanted you to know A, you do all of those things, make us feel all of those ways, but you never win. We do! You may have Alopecia, but we are Alopecians and those extra two letters N & S, aren’t just letters, they stand for nothing other than Natural Strength. We possess tons of the stuff and trust me when I say, we will always, always win.

Love,

Sheree

(@nohairdontcarexo)

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SYBILLE EBNER

Dear Alopecia

It's me, Sibl. Do you remember me?

We met last summer in Croatia on a lovely camping site. I was shocked when I recognised you in the mirror, but you smiled at me with a shiny grin that I won't forget for the rest of my life.

You smiled all through my holidays, you smiled at me in the morning while I brushed my hair and in the evening while I brushed my teeth, and you kept smiling at me when I came home, even while working as a yoga teacher.

When I bowed in Sukhasana to welcome my yogis, I was thinking of you – in every single yoga class.

During the first weeks, I thought of you every minute. I checked my hair in every mirror. I looked into every reflective window. I asked my husband and my son if my hairless little circle was covered by hair, while my daughters thought about wig colours and bald styling options.

But with autumn, my calmness came back.

I still thought of you when meditating on my yoga mat, but I sent you mindful breaths and a smile instead of hateful thoughts and bitter tears.

I made beanies and caps for you - not to cover you - but to keep you warm in winter.

And I talked about you to all my family, friends and fellow yogis, just to tell them, that we are friends now and will be for the rest of my life.

Whenever I talked about you, the reaction always was the same:

At first, everybody looked shocked. Then they smiled and said charming things that touched my heart. Talking about you was the best thing I could do. It gave me the power to fully invite you into my life.

And so, I nearly forgot about you –

until one day.

On this special day, I realised that my brush was full of hair. I clean my brush every day, so the hairball I was looking at was a new one. I took an interested look in the mirror to check my scalp –

and saw a lot of it. The whole left side of my head seemed to shine, as my skin is white and my hair is brown.

While getting ready for work I also realised that I lost many of my eyelashes. Maybe you took them for good.

At night, when my kids were sound asleep, I sat on my yoga mat, thinking about you and how I first met you. I was a little girl when I made my acquaintance with you. My mum was your first friend in our family. We didn't really talk about it back then. Being a bald woman was a shame for my mum, and I remember that she tried every possible treatment, invested a lot of money, took dozens of pills and went to irradiation – without success. Losing her wonderful dark hair was big emotional stress for my mum, so she decided to wear a wig. Alas, she always found herself the ugliest ones, that made her look like an old woman to me. She never cared for all her wigs – no brushing, no washing, just wearing and being unhappy with her own appearance.

I remember watching her behave like this, slightly disgusted, and I promised myself not to act like her, if baldness would hit me one day.

And here you are.

I have to confess that it was hard to see you as a friend, that it hurt me to watch my hair fall out.

Every morning, when I decide to put on mascara, my heart does a little jump. I once was proud of my eyelashes, now there are nearly no lashes left.

Sometimes I could cry, just because this white glance under my remaining hair hurts my soul.

Sometimes I could scream, just because it's so exhausting these days to dress my hair properly.

But then, most of the times, I share the bathroom with my daughters, you've met them already, sweet little ladies –

and I don't want to look like a picture of misery to them. I want them to be strong women one day. Self-confident and brave, and I would like to be their role model.

So I swallow my tears, my doubts and my misery. I put a big smile on my face and a beanie on my head, and I wear the earrings that will catch everybody's attention according to my daughters.

Maybe we'll spend more hairless time together, maybe you will move on, I don't know. But I do know that I will accept you in my life, that I will take you by the hand and lead you into the future, because:

My hair doesn't define who I am, it's just hair.

That is the big lesson you taught me so far.

Losing my hair does not change me as a person, it doesn't change the way I love my family or the way my family loves me.

Losing my hair has shown me once more that my family stands behind me, always and ever, and that I am the strong woman I always wanted to be.

Nothing in the world will change that –

thank you for this lesson in life.

Yours faithfully,

Sibl

(@sibl_and_the_wheel)

ACKNOWLEDGEMENTS

There are many people I would love to acknowledge individually, but we would be here all day so I'll try and keep it short and simple.

To the people who took part in this project, I want to say a big thank you for sharing your story with me and the world. You're all brave, beautiful souls and I am so happy to have met you through this amazing community that we share.

To the friends who are constantly there for support. You know who you are. I love you and cherish you with all my heart.

To my family who have been on this journey with me since the beginning and have always been there for me.

To my beautiful Doreen who without our FaceTime conversations, I would be an utter mess. Thank you for providing endless laughter in this sometimes dark void I find myself in.

And to my best friend. My rock. My soulmate. My biggest fan if there ever was one. Mutay, you are the light of my life and I know you will always be there for me when I want to vent, cry, scream at the injustices I feel. Love you always and forever.

Thank you so much for taking the time to read this eBook. A lot of love was poured into this and I really appreciate everyone who has read it. Please feel free to donate to Alopecia UK or the charity in your respective country. Alopecia UK's "overall research aim is to provide hope and confidence to people with alopecia by funding research into its causes, with the aim offinding treatments, and ultimately, a cure." Every penny counts.