

Alyssa — This is my first time sharing my alopecia story

My alopecia story is a fairly short one. In November of 2017, my first patch of alopecia appeared. By March 2018, I was bald. By May, I had no eyebrows or lashes.

I always liked my hair well enough, but never thought of it as something that defined me. When I began to lose it, my biggest priority was maintaining an outward appearance of normality. I wasn't unwell in any way and didn't want anyone's pity, so I was determined to hide my alopecia from the world. I'm lucky in that I wore a hat to work every day, so I could hide the coalescing bald patches with headbands and just put the hat on when I got to work. As things progressed though, the scraggly strands that remained became harder to hide and the person staring back at me in the mirror looked sickly. The weekend before my 28th birthday I shaved my head to get a custom wig made. I was surprised to find that I actually felt much more myself without hair – like I'd taken control of something that for the previous few months had been taking control of me. And, as it turns out, my bald head isn't too badly shaped! I bought an interim wig which was a few shades too dark and sat differently to my natural hair, but fortunately I've changed my hairstyle often enough in the past that most people took the change without batting an eyelid. I told myself I could live with this – as long as I could keep my eyebrows and eyelashes I'd be fine.

When my eyebrows and lashes began to go, my confidence plummeted. When they were gone completely, looking at myself in the mirror became the biggest challenge of the day because I didn't recognise the person staring back at me – I was completely disconnected from her. I've always kept things natural so the idea of using makeup and falsities to define my features was also very difficult to grasp. I was so sure that everyone would notice and I somehow felt that was the worst thing possible. the classes. I now attend more frequently with friends and am excited by the prospect of socialising with post-workout coffee dates (in our active-wear, of course).and are happy to tell the world about it, there are many others who will be very content to keeping their alopecia to themselves – and that is also totally fine.



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My mental health suffered significantly. I was so incredibly lucky to have supportive friends, family and a GP around me who were understanding, kind and patient, but along with my hair I lost my confidence and my identity. I withdrew, engaging with others only when I had to and only enough to get by. I had no desire to socialise and while I was sometimes able to force myself to attend planned events, I certainly never actively sought them out. I stopped exercising – something that has been central to my life for as long as I can remember. I told myself that if I could only accept my alopecia, my mood would improve. Eventually I sought help and began treatment for depression and finally, thankfully, I was able to see everything so much clearer. It turns out that in fact I needed my mood to improve and to care once more for myself in order to accept my alopecia.

It has taken me 12 months, but I'm now in a position where I once again feel comfortable in my own skin. With my hair, eyebrows and lashes on, it's not quite the same person staring back at me in the mirror, but it's someone I have connected with and I'm content that this is the new me. Completely bare, on the whole I'm comfortable, although there will always be rare days where life throws a little curve-ball at me and the image in the mirror doesn't sit quite as well.

Throughout the last 12 months, one of the biggest hits has been my reluctance to take part in exercise including running and team sport, for fear of accidentally exposing my secret to the world if my hair were to misplace itself. A friend of mine opened an indoor cycling studio at just the right time and attending classes – infrequently at first – allowed me to exercise by myself in a dark room on a stationary bike with little risk of people realising my secret. Over time, as my fitness has improved in parallel with my mental state, I've been able to engage much more in

I am so incredibly grateful for the opportunity the Alopecia Areata Australia Foundation has provided me in sponsoring my membership with Studio 360 Cycle. I'm excited to take part in a month-long challenge they have coming up and to push myself physically like I used to.

This is my first time sharing my alopecia story. Recently I've been much more comfortable with my alopecia and have had non-confronting conversations about it with friends and colleagues when talk has turned to hair or lashes, where previously I would have clammed up and quickly diverted the conversation. I think it's important to appreciate that everyone's alopecia story will be different and everyone will have different ways of tackling the challenges that come along with it – especially with how it affects their identity and sense of self. While it's incredibly inspiring to observe those who have totally embraced their alopecia and are happy to tell the world about it, there are many others who will be very content to keeping their alopecia to themselves – and that is also totally fine.

Alyssa

The last 4 months of sponsorship through the AAAF for membership with Studio 360 Cycle, an indoor cycling studio in SA, have been incredible. Cycling at the studio has given me an opportunity to exercise and challenge myself physically without fear of accidentally misplacing my “hair”, which has been a big fear of mine since my alopecia developed. What’s fascinating, though, is that more engaged I’ve been with the sponsorship and the studio, the less my hair (or lack-thereof) actually matters...

Studio 360 held a “hustle” challenge a couple of months ago that encouraged people to make goals to push themselves physically. As part of the challenge I attended 24 classes (of hard-core, sweat-inducing spin) in 28 days. I was forced to make time for this physical activity – for me – prioritising it around work, study and family life. The challenge gave me something positive to focus on and to strive towards. It’s been many years since I’ve really pushed myself physically like this and the boost it gave to my confidence and fitness was incredible. It’s funny what having a physical (achievable) goal can do for your mental health too... I felt focussed, determined and in control; characteristics that had somehow slipped away over the preceding 18 months.

Since alopecia first appeared in my life, I’ve been pretty private about it. Applying for this sponsorship and writing about “my alopecia story” were the first times I’d intentionally shared my story beyond my close network. My confidence has slowly grown over the last 12 months, but it’s still not something I’ve felt like shouting from the rooftops. As part of the sponsorship arrangement I organised an awareness and “give-back” ride through the cycling studio. It was wonderful to see all money raised from the event go directly back to the AAAF, but just as importantly, it provided an opportunity for people to speak openly about alopecia in a bid to normalise it just a little. I’ve become pretty good at hiding my alopecia, initially intentionally and more recently because my new appearance is how I identify with myself, but I stepped out of my comfort zone for a night and had a lot of fun doing so. Donning a silver wig, I spoke publicly for the first time about alopecia; what it is, what it means to those it affects and how we work to overcome the challenges it presents. Now that other members at the studio know about my alopecia (and, surprise, surprise - don’t think any different of me!) a further weight has fallen from my shoulders because I know it doesn’t matter if I don’t put my eyelashes on for a class, or if my wig slips around a little on my sweaty head. No-one is going to judge me, no-one actually cares (which were terrible fears of mine when everything first started snowballing out of my control). There have been moments when, with sweat pouring down my face and neck from under my silicone wig cap, I’ve been tempted to rip it off and ride bald. I haven’t quite convinced myself to do it yet, but you never know, maybe one day I just might...

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In the time since my last check in, very little has changed. However, this is a wonderful notion as it reflects a sense of normality and routine that has come of both my alopecia and my commitment to improving my fitness.

Throughout this time I've been reminded of the importance of exercise in maintaining a sense of self and optimising well-being. It's increasingly acknowledged that alopecia goes hand-in-hand with a reluctance to take part in exercise, but by no means am I the only member at the cycling studio who has faced challenges over the years. The more involved I've become with the studio, the more I've learnt about the incredible people around me who've made it through far worse than I could ever imagine; be that cancer, debilitating injury or the loss of loved ones. Others still have overcome personal battles with smoking and mental health. The strong, supportive, encouraging community that has grown during the time I've had my membership with Studio 360 through the AAAF has been wonderful to be a part of.

As my sponsorship period draws to a close, I'm looking forward to what I can take away from this incredible opportunity. I'll be taking part in another "hustle" – a 24-class challenge – over the coming month and my aim will be to maintain my achievements through to the end of my sponsorship period. As my focus then shifts heavily to studying, I know that I'll be so much better for the physical strength, the mental resilience and the sense of self-acceptance that has been afforded to me through this sponsorship.



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I am so very grateful for the incredible support I've received through the sponsorship program with the Australian Alopecia Areata Foundation. I was nervous about applying for the program... it was the first time I'd really put words to my alopecia universalis and how it had impacted me. Looking back now I have no regrets!!

The last 6 months or so have taught me a lot about myself. I've been reminded of the significance of physical activity and fitness in my life. I've rediscovered the importance of the company of others. I've learnt to challenge myself and push myself beyond my comfort zone. I've learnt that the biggest barrier to me getting out and re-establishing a normal life is me! And I've also learnt that that's ok, and not to beat myself up about it.

12 months ago, I was terrified of revealing my secret to the world – whether accidentally or intentionally. I did my very best to hide my alopecia and freaked out whenever anyone around me started talking hair, lashes or brows. Something that should seemingly have been a superficial, insignificant physical change in my appearance had an insanely significant effect on my sense of identity and feelings of self-worth. While I still don't shout about my alopecia from the roof-tops and don't leave the house without my hair on (or recently a scarf if I'm just popping over to mum and dad's – baby steps but still progress!), I'm now very comfortable talking about it. Eyebrows and eyelashes are so trendy now that when I get complements on mine, people are blown away to find out they're stuck on.

I suspect that time has had a large role to play in my acceptance of my alopecia, but I definitely wouldn't be where I am now without the incredible opportunities afforded me by the AAAF's support of my membership with Studio360 Cycle, an indoor cycling studio in Adelaide. The chance to exercise on my own terms, in a dark room, without fear of accidentally misplacing my hair; the gradual but significant improvement in mental health that comes hand in hand with improved physical health; and the incredible encouragement and support of the extraordinary trainers and wonderful members can't be adequately articulated.



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To anyone grappling with the unique challenges alopecia brings: please know that you're not alone. Alopecia is devastating, isolating and really does change people's lives. I still remember the terrible guilt I felt at being so upset by this (not so) "silly little physical thing" when I still had my health, I still had my loved ones and I still had my whole life ahead of me. It's ok to not be ok, but make sure you reach out to the people who matter most to you including friends, family and also very importantly your GP.

To mark the end of my sponsorship period, I decided to challenge myself well and truly one last time. Here's a little video I made documenting the process... My sincere apologies for the shoddy editing. I hope you enjoy it!!

Love Alyssa.

