

Living with no head coverage.

The following is a story being shared by two people; a mother and a daughter, who have experienced all forms of Alopecia Areata for 20 years. Kylie and Joanne's story is a moving encounter on their daily life's experience and the choices they have made along the way.

My name is Joanne and this is story about my daughter Kylie, who is the eldest of 3. She has a younger sister and brother.

I want to tell you about Kylie's journey with Alopecia Areata and how my husband & I came to support Kylie's decision to be 'a la naturale', that is, not wear a wig. We want you to realise that it is okay to decide not to wear a wig, and we feel this decision is best if it rests with the person who has any form of Alopecia. Areata

Kylie was 6 years old when having her first bald patch. Initially my husband & I questioned ourselves as to why this would occur and thought maybe it was the tight pony tails I put her hair in for school.

Our Doctor said to us **"Don't hide her away, get her out doing things."**

The Dermatologist recommended Cortisone tablets and a cream on her head which made her hair grow curly, however we noticed that her personality changed, becoming irritable and easily upset so we decided to stop using Cortisone. Over the next 12 months Kylie's hair fell out completely – eyebrows, eyelashes, everywhere. One day she commented to her younger sister – "Crystal your arms are hairy". What a strange thing for a young girl to say and on further discovery we found that Kylie had no hair on her arms – or legs either.

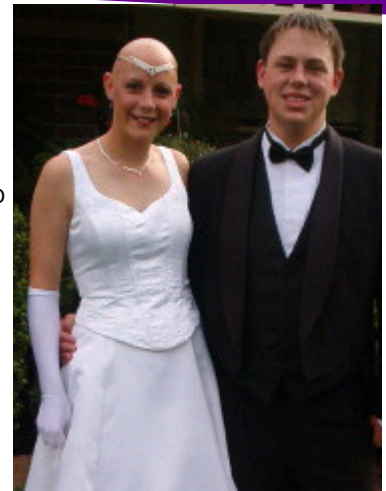
We tried to cover up the lack of hair with hats – there was a TV show called Punky Brewster where there was a girl who wore lots of different hats that Kylie liked so we had a huge variety of hats for her to wear.

I'm Kylie. During this time I was also teased at school and kids wanted to see why I was wearing hats all the time. Kids would tease me at recess and lunch times, sometimes pulling off the hats and laughing at me. I remember sitting in the classroom doorway so I could be away from all the other kids. At this time I did not stick up for myself, I would just hide! My grade 2 teacher would let me change hats during the day so I could have an outside hat and an inside hat. She would allow me to go into the classroom before all the other kids so I could change hats without them seeing.

We also went down the path of naturopaths, Chinese Herbalist, other doctors, etc and of course came to Alopecia Support Group where we discovered – to our dismay – that there is no one cure for everyone. However we continued to look for ways that might make Kylie's hair grow back – special shampoos, lotions, tablets, etc

For us this was the worst thing that could happen – our little girl (the eldest in our family) had something supposedly wrong with her.

She was teased and I had to realise that I could not be with her protecting her every second of every day. She was called 'baldy'.



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I had to help Kylie be strong so I needed to teach her to be able to answer back to people. I got her to practice with me by – putting her hands on her hips and say “so what” or “big deal” or “tell me something I don’t know”. This gave her the confidence to say something back to these children.



My Mum’s suggestion was to stand in front of the mirror looking yourself in the eye and say “I am Great, I am Beautiful” which we did also. We are also fortunate to have an extremely supportive broader family & some good friends that accepted Kylie the way she is.

I also remember a sign that one of the girls at the Alopecia Support Group had, “God made everyone bald, and covered the ugly ones with hair”. Some people might not like this but it hit a chord with me.

Once I had learnt these sayings I started to use them at school when kids picked on me. I found the comments that pointed out the obvious, like “so...” were the most effective because the bullies didn’t get the reaction they wanted and after a few times of telling them, they eventually left me alone. When sticking up to bullies I found pretending to them that I was OK with it, made them find someone else to pick on, because to them I was not bothered by it. However, I would often go and cry once they left me alone, so they didn’t see me cry.

We made the decision to wear a wig which Kylie wore in Grade 3 at school. The wig was hot, uncomfortable and back then (15 years ago) it was obviously a wig even though it was made from real European hair, and it was expensive. Kylie would arrive home from school and immediately throw the wig off onto the floor. When the doorbell rang Kylie would go into a panic running off to put the wig on before anyone could answer the door. Over that year the wig was helpful in allowing Kylie to ‘look normal’ like other children but it also made her very self conscious. Hair grew under the wig during this time, which made the wig not as secure and of course it was pulled off at school one day. Kylie later felt comfortable to take off her wig for friends who came to play.



During that year I was at school, there were kids that worked out I was wearing a wig and some pulled it off and laughed. There were days I would not want to come to school or I would hide in the girls’ toilet during recess and lunch so I would not have to deal with the teasing. However most of that year, I had fun playing with the other kids and most of them didn’t notice. I would be very careful in the yard, making sure I didn’t hang upside down on the monkey bars or swing around at a fast speed.

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The end of that year we went on holiday to the beach with Kylie's cousins who knew her without hair, with the wig and without the wig and who were similar in age to her. I encouraged Kylie to go without the wig because she had some hair, no-one else at the caravan park knew her and it would be easier going to the beach.

I was very hesitant at this point but with a supportive family I slowly forgot about it and played like a normal kid.

At the beginning of the next school year – Grade 4, aged 10 – Kylie went off to school without the wig, however she felt very uncomfortable. Her school teacher comforted her for the first couple of days as she was in tears, however I thought this was the best thing to do. Kylie's hair fell out very gradually over the next 9 months, including eyebrows and eyelashes. Kylie did not want to go back to wearing the wig that she had hated so much. During this time we got her involved in playing netball, riding horses, swimming and it really was much easier to do these activities without a wig. She did not have to worry about the wig coming off or feeling too hot.

After not wearing the wig for a while and getting used to a 'normal', not wig life I hated the thought of going back to hiding who I was. Going back to running off to find the wig and putting it on before anyone else but family would see me. I could run about and not stress about the wig falling off. I would not get so hot. I could hang upside down on the monkey bars and not worry. Yes, kids still stared and pointed, but if I didn't look for kids picking on me and just go about my merry way, I would still have a good time. Some children started to pick on me once my hair started falling out that year. Again I would stand up for myself and say things like "yeah I'm bald, what are you going to do about it" or I would find something about them to throw back at them like "at least I don't have curly hair" or "at least I have friends".

During this time there was a bridge collapse disaster in Israel that involved people we knew – some who were trapped under the bridge in the water and whom we believed might not make it.

There were other people we knew (through our business) who had children who were blind, disabled and we were able to look at our situation as being not that bad.

There was a girl at Kylie's school the same age as her who developed leukemia and died at age 13.

My cousin Rachel (2 years older than Kylie) was born with cerebral palsy and is not able to do much for herself at all. All these instances helped us to realise that Kylie was not sick, her hair fell out but she was healthy and able bodied. This put it all into perspective, and so the next thing was to work out how to learn to live with this baldness.

The best thing for Kylie was to be natural and not hide her baldness. We helped her to feel good about herself – if she was not teased about being bald she would have been teased for having different shoes, or different jacket than everyone else, or something else.

Kylie became involved in playing representative netball and most people in the netball world know of Kylie and realise she has Alopecia Areata. It was also about informing people that Kylie did not have cancer, that she had this condition called Alopecia Areata and that she was not sick.



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Once I decided not to wear a wig anymore I found it easier to talk to people why I didn't have any hair. People were often scared or unsure how to ask me about my condition, but by being open about it and explaining to them exactly what it was and why it happens I found my friendship group grew bigger. They knew what it was and why I looked that way. Friends then began to forget about the 'no hair thing' and sometimes even forgot I didn't have hair, even asking me for a hair brush on the odd occasion.

Next we had to be careful which high school to send her to.

This began with me interviewing prospective school principals, explaining Kylie's Alopecia and asking the question "What will you do when, not if, Kylie gets teased for being bald." They all had varying answers to this.

We also talked to various parents and teachers who were parents with teenage children to find out what the schools around the local area were like.

We decided on a Christian College in Pakenham that promotes a caring, Christian attitude and who looks after the individual students. This was certainly a fantastic school where Kylie was never teased. I remember when Kylie first began there, the Canteen Supervisor commented to me on how confident Kylie carried herself and that she had plenty of friends. I certainly was relieved.

In my teen years and early 20s I would often blame the Alopecia for things. I would think things like;

- I would never find a boyfriend
- I would never get married
- I would never get a job, etc.

For some people Kylie being natural is confronting but for Kylie & us it is Kylie being Kylie. Kylie learnt at a young age to celebrate who she is and I want to celebrate that with her, and I am her biggest cheer leader!!!

She certainly still feels uncomfortable wearing anything on her head.

Kylie is a person who feels that if she wore a wig that she would be hiding under it, and not being true to herself.

Even now I hate wearing anything on my head. Hats, party wigs, anything. This is because I had such a bad experience with them when I was little and I know it sounds strange but to me I hate the reaction of people when they look at me as I take off a hat. To me it is like they are shocked then I take off the hat, but if I don't wear anything to begin with people can see that I'm not trying to cover it up and I am confident with how I look (most of the time).

Now ... if I wore a wig I don't know how

- I would tell new friends I had Alopecia,
- How and when do you tell a new boyfriend?
- How would I bring it up when going for a job?
- How would I tell my children in the future?

All these sorts of questions I don't have to answer, because it is easy to see. All I have to do is explain what Alopecia Areata is and a brief rundown of my life with it!



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Over the years I have come to value those now close friends from high school that have stuck together and helped Kylie through some difficult times. Every single time Kylie went out to a night club or bar, someone would come up to Kylie to ask her about her 'baldness'.

These friends would realise when Kylie was feeling vulnerable and they would shield her. They could tell when someone was going to talk to Kylie about being bald and they would place themselves between him and her to stop them. They looked out for her and on the odd time when Kylie did not feel like going out they hung out at each other's place. Awesome friends are Gold!!!

I am now a primary school teacher, I play netball and I am engaged to my fiancée Mat and getting married in March next year.

Her first year teaching was with Grade 1 and she had a young girl in her grade with Alopecia. What a role model is Kylie for this little girl and for all the children in that school. The school has had a crazy hair day raising funds for AAAF, which raises awareness not only for those children attending the school but the community in which it is.

There are some days where the alopecia will get to me and I will have a little cry but reminding myself of the things I have, as well as having the best fiancée in the world helps me to cope.

Looking back at the things that have helped Kylie deal with being bald the most, I would have to say it is accepting herself. The things that we did to help this happen were:

- ~ teaching her to stand up for herself, ie have an answer for those teasing her;
- ~ getting her out doing activities that other young girls her age were doing;
- ~ finding a high school that is accepting of differences; and
- ~ treating her as though nothing was different about her (we treated her the same as our other 2 children).



Looking back now I am so grateful to my parents who helped me to become who I am today. Part of me thinks that I have been put on this earth to make other people aware of all forms of Alopecia Areata. I'm not saying this is for everyone, but now that I am older and I realise that I seem to be the only adult that goes about my life not covering up the Alopecia, I wanted to talk to you guys about ways of dealing and coping with Alopecia. For me coming to the alopecia days and events I found they were about covering it up – wearing a wig for most is how they deal with this.

I hope by reading this, this has given you another way to cope with your form of Alopecia Areata.

Thank you for reading our story.

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