

How would your parents describe it?

- It's when you have patches or are bald
- It's an autoimmune condition
- You lose your hair and there is no cure
- It's ok
- It's nothing to worry about and a lot of people have it
- They don't talk about it
- Your immune system attacks your hair.
- Life changing.....the body's immune system is attacking the hair follicles so the hair falls out. It may or may not come back
- They say that it frustrates them as they have tried lots of treatments to try to help.

How do people you meet see you?

- They stare
- Tell me how beautiful my hair is
- They point at me and talk about me
- They don't say anything
- I don't know, I have never thought about it
- People tell me I'm beautiful.



“My name is Georgia, I'm seventeen years old and I've had Alopecia Areata since I was four. George Orwell once said that happiness can only exist in acceptance. I tend to agree with him. What he forgot to mention is that acceptance, like happiness, is not a moment or event, but a process.”

How would your friends describe Alopecia Areata?

- They never mention it
- They are protective of me when I get bullied
- They don't see it
- My friends don't know
- None of my friend's care — they are really supportive of me and help me with problems
- My group of friends made me realise that it's OK to be different
- Bald patches.

Do you do the things your friends do?

- I swim, play competitive netball and do ballet
- I do everything my friends do
- I'm very active and have heaps of trophies in AFL, golf, soccer, tennis, but I like motor bikes and skateboarding
- I'm into music and tennis
- I do gymnastics and the guitar
- I got 3rd place in World Karate.

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Refer to the www.aaaf.org.au for discussion groups/ social network links and youth ambassador contact details.



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Teenagers talking about Alopecia Areata



Alopecia Areata is hair loss from the scalp, eyebrows, eyelashes and the body. It's an auto immune condition. Our immune system is what attacks germs that would make us sick. In this case the body treats its hair follicles as foreign tissue (germs) and slows down or stops hair growth, but the hair never dies, so the hair always has the potential to regrow. It is not contagious and it doesn't cause any physical pain.

Find a way that you're comfortable telling people what Alopecia Areata is because your way is unique and so are you.

Teenagers with different forms of Alopecia Areata were asked the following questions and these were their responses:

How do you tell others you have Alopecia Areata?

- I don't
- I only tell people about it if they ask
- My response changes depending on why they are asking. I either explain that my immune system attacks my hair, or I just say I'm sick
- I explain that my immune system, the same thing that attacks foreign bodies like germs and viruses, decides to attack my hair roots instead
- When I tell people I almost always have to do the "It's not cancer, I'm not dying, you can't catch it" speech as well
- People naturally think I have cancer, I say I don't have cancer I have Alopecia. They say what's Alopecia? I answer my immune system is attacking my hair follicles and making my hair fall out in patches
- I say that I wear a wig and I don't have cancer then explain that I have Alopecia Areata and that it's not life-threatening
- I tell them I have a medical condition with no cure.

"People now have a better understanding of who I am and why I don't have hair."

What is the biggest problem?

- Looking different
- People thinking I'm sick and asking if I have cancer
- Having to wear a hat all the time
- Having my wig pulled off at school
- Having to wear sunscreen – Always!!!
- Having to explain it all the time
- Trying different treatments that don't work
- Visiting the doctor a lot
- Family and friends asking how my Alopecia is
- Not feeling comfortable with my looks
- People always staring
- Having trouble tying up my hair so no one can see that it is actually a wig
- Not knowing if or when my hair will grow back
- Not knowing why it happens to me
- It grows back and the worry of it falling out again
- Feeling helpless, like there is nothing I can do to grow my hair
- Acceptance.

How do you say it?

Alopecia (al-oh-PEE-shah) means hair loss. When a person has a medical condition called Alopecia **Areata (ar-ee-AH-tah)**, it means the hair falls out in patches.



"I'm Steph and I'm 13, to me bringing my community together on knowing what Alopecia Areata is, was very important. People now have a better understanding of who I am and why I don't have hair."

What good things happen from having Alopecia Areata?

- Don't have to get hair cuts
- I have multiple wigs, so multiple looks
- Don't have to comb or wash my hair
- Don't have to worry about nits
- I made a new friend who also has Alopecia
- My friends and whole school supported me and my fundraising venture.

What helps you deal with Alopecia Areata?

- Talking to my friends about it
- My friends not focusing on my baldness
- My parents being there for me when I have a bad day
- My family always being there for me
- Talking to others who have Alopecia.