



PARENTS PACK

Created by the Australia Alopecia Areata
Foundation Inc.

INTRODUCTION

Whether you have been newly diagnosed or have been living with Alopecia Areata for some time, AAAF recognise that when a child has Alopecia Areata, this affects the whole family. Information provided in this Pack is based on psychological research, AAAF's committee members and our broader community's lived experiences. Advice, stories and quotes have been shared throughout this pack to aid you and your family to have a positive journey.



Alopecia Areata
..... it's life changing

Table of Contents

About Alopecia.....	2
Frequently Asked Questions:	3
How to Explain Alopecia to Young Children.....	6
Understanding your options.....	7
Support for your family.....	9
Our Stories.....	11
Community Q&A	18
School and Bullying.....	20
Siblings of Children with Alopecia Areata	22
Children of Parents with Alopecia Areata.....	23

About Alopecia

Alopecia Areata is a disease that results in the loss of hair on the scalp and elsewhere on the body.

It is often not well understood and can be confusing. Alopecia Areata is believed to be an auto-immune condition. This means that our immune system, which is supposed to defend against disease and infection, begins attacking a part of our own body. For people with Alopecia Areata, the body treats its own hair follicles as foreign tissue and attacks them, which slows or stops hair growth.

There are three main types of Alopecia Areata:

- Alopecia Areata, which means patches of hair loss.
- Alopecia Areata Totalis, which means complete loss of hair on the scalp.
- Alopecia Areata Universalis, which means complete hair loss to the entire body, including eyelashes, brows, and even ear and nose hair.

Alopecia Areata	Alopecia Totalis	Alopecia Universalis
Patches of hair loss	No hair on head	No hair on body



In all forms of Alopecia Areata, the hair follicles remain alive and are ready to resume normal hair production whenever they receive the appropriate signal. That means that hair regrowth may occur spontaneously even without treatment and sometimes after many years of hair loss. Each person experiences the condition differently. The hair may grow back and fall out again many times, or cycle through various types of alopecia throughout their lifetime.

Understanding what category of Alopecia Areata your child may have can be very confusing. Many people shorten the classification due to the difficulties in pronouncing the full names.



Frequently Asked Questions:

Who gets Alopecia Areata?

Alopecia Areata occurs in males and females of all ages and races; however, onset most often begins in childhood.

Is it life threatening?

No. Alopecia Areata is life changing, and its sudden onset, recurrent episodes, and unpredictable course can have a deep emotional and psychological impact on the lives of those affected by this disease. People with Alopecia Areata are fully capable of living happy, healthy lives and there is no reason the condition should hold them back.

Is it common?

Roughly 1-2% of the population have some form of Alopecia Areata. It is best to describe it as "not uncommon".

What causes Alopecia Areata?

Alopecia Areata is considered an autoimmune disease, where the immune system mistakenly attacks its own hair follicles. Why the body does this is still unknown. Many people say the condition is stress induced, but there is little consistent scientific proof of this.

Do other autoimmune diseases impact Alopecia Areata?

People with Alopecia Areata may have a higher risk of other autoimmune diseases such as thyroid disease, vitiligo, or eczema. Some people with Alopecia Areata have a family member with the condition, but not all. People who have had eczema or a thyroid disease are more prone to alopecia. Susceptibility is most likely due to a combination of genes, but not directly hereditary.

Is it infectious?

No. There is no way in which a person with Alopecia can transmit the condition to anyone else.

Is Alopecia Areata inherited?

Scientists believe that there may be a number of genes that predispose certain people to the disease. It is highly unlikely that a child would inherit all of the genes needed to predispose them to the disease.

Melissa:

Alopecia has helped me learn not to worry with what the future will be, but to live in the moment and take each day as it comes

Even with the right (or wrong) combination of genes, Alopecia Areata is not a certainty. Studies suggest that in identical twins, who share all of the same genes, the concordance rate is only 55 percent. In other words, if one twin has the disease, there is only a 55-percent chance that the other twin will have it as well. This shows that other factors besides genetics are required to trigger the disease.

How does it start?

The body's immune system wrongly attacks the growing cells in the body's hair-producing follicles, where the hair starts to grow. This stops them producing new hair and causes existing hair to fall out. The cells which produce the hair, the follicles, do remain active so there is always the potential for hair to start re-growing.

What body areas are affected?

The scalp is the most common area and generally the first area to experience hair loss. Hair loss can also occur from the eyebrows, eyelashes, facial hair, arms and legs. Fingernails may also be affected with pitting.

What does it look like?

The patches are smooth and round, sometimes with few remaining hairs in the centre. Around the edge of the patch some stub-like hairs can usually be seen (often called "exclamation mark" hairs, as they are thicker at the tip than at the scalp level).

Can the loss be diffuse?

Less commonly, some hair may be lost over wide areas, causing general thinning of the hair. This can cause "hair to turn white overnight" by selectively affecting dark hairs and leaving grey hairs.

How is it diagnosed?

Alopecia Areata is diagnosed through a medical history and physical examination. Your doctor will ask questions about the hair loss, look at the pattern of hair loss, and examine the scalp.

Hair can be plucked and examined under the microscope and if tinea is suspected, hairs may be taken for culture. For very careful study, a small biopsy may be performed for microscopic examination of the scalp skin. In most cases, tests are performed only if there is a need to assess general health. Blood tests do not show any abnormality in people with Alopecia Areata.

How will Alopecia Areata affect my life?

This is a common question, particularly for children, teens, and young adults who may live with the effects of Alopecia Areata for many years. The comforting news is

that Alopecia Areata is not a painful disease and does not make people feel physically sick. It is not contagious, and people who have the disease are generally healthy otherwise. It does not reduce life expectancy, and it should not interfere with going to school, playing sports and exercising, pursuing any career, working, marrying, and raising a family.

The emotional aspects of living with hair loss, however, can be challenging. Many people cope by learning as much as they can about the disease, speaking with others who are facing the same problem, and, if necessary, seeking counselling to help build a positive self-image.

Can the hair grow back?

There is every chance that your hair will regrow with or without treatment, but it may also fall out again. No one can predict when it might regrow or fall out. The course of the disease varies from person to person. Some people lose just a few patches of hair, then the hair regrows, and the condition never recurs. Other people continue to lose and regrow hair for many years. A few lose all the hair on the scalp; some lose all the hair on the scalp, face, and body. Even in those who lose all their hair, the possibility for full regrowth remains. The course of Alopecia Areata is highly unpredictable, and the uncertainty of what will happen next is probably the most difficult and frustrating aspect of the disease. The re-growth can be any texture and colour, from fine, downy white hair, to hair identical to your original hair colour and texture

Does Alopecia Areata affect general health?

No. All aspects of general health are unaffected - apart from the rare associations with other diseases. People who are affected by Alopecia Areata are usually otherwise healthy.

Nicole:

Breathe, all will be ok. Alopecia will be part of us, but not define us.



How to Explain Alopecia to Young Children

Alopecia can be difficult enough to explain to adults, so explaining the complexities of how autoimmune conditions work to children can feel daunting.

However, AAAF believes that it is very important for children with Alopecia Areata to understand what is happening to their body as much as is possible for their age. Understanding the condition will help children to feel more in control of what's going on and more confident, and help to combat feelings of fear or anxiety.

Below is an example which may help you to explain the condition to children.

- Everyone has a system in their body which helps to keep them healthy. It works like a troop of very tiny soldiers, which receives orders from your brain when you are sick or injured. These soldiers (called the immune system) seek out the things that might make you sick and attack them, like germs or viruses, in order to keep you healthy. Sometimes, these soldiers get confused by the orders they get from your brain, and instead of attacking germs or viruses they attack parts of your own body. This is what happens with alopecia. Your soldiers don't understand their orders, and they begin to attack your hair follicles – the place your hair grows from. This is what makes the hair fall out.

Kaylene:

You will be okay. All that matters is that you have confidence in yourself. Love yourself because you have many family and friends that love you too.



Understanding your options

Treatments

Although there is no cure for Alopecia Areata there are medications available that can help hair grow back in some cases, at least temporarily. Some important things to keep in mind are outlined below.

Shea:

*Don't let Alopecia beat you!
You are stronger and more amazing
than you think and you will come out
on top!*

- Although these treatments may promote hair growth, none of them prevent new patches or actually cure the underlying disease.
- Consult your health care professional about the best option for you. A combination of treatments may work best.
- Ask how long the treatment may last, how long it will take before you see results, and about the possible side effects.
- Seek second opinions from other professionals when necessary, as different practitioners may suggest different options.
- Seeking information from other people with Alopecia Areata can be a great way to find out more.

Electing not try any treatment is a completely valid option. Many people find the emotional ups and downs attempting treatments to be more distressing than accepting the condition and choosing to move forward. AAAF believes that supporting emotional and psychological health is vital during this time, and recommends reaching out to a mental health professional if needed.

When discussing any treatment for a child with Alopecia Areata, AAAF believes it is always best to try to include the child in the decision-making process, as much as is age appropriate. Making sure they understand what is going on will help to combat feelings of anxiety and fear, and having a say in their medical treatment will help them feel more in control of the condition.

Wigs and hairpieces

Many people with Alopecia Areata choose to wear wigs or other hairpieces. These can help them feel a sense of control over their appearance and their condition, and feel more confident when in public.

There are many different types of wigs and hair pieces available and buying a wig for the first time can be challenging. It can also be a major financial investment, so to minimise the risk of getting something you're not happy with, AAAF has a guide available on our website which may help you decide what is right for you. Our Wigs for Kids grant program is also available to assist in the cost of

purchasing a wig for children under the age of 18.

In general, AAAF does not recommend wigs for very young children, as they can be difficult to care for and may get in the way of kids during normal play.

Hats and scarves

It is important to note that wigs and hairpieces are not the only way to manage alopecia. Many other people feel that wigs are uncomfortable or get in the way of day to day life. Once again, there is no right answer – just what works best for your situation. These people may choose to wear hats or headscarves to keep their heads covered or protected from the weather.

Some other people prefer not to wear anything at all on their heads. This, again, is absolutely fine. How individuals manage their alopecia is up to them. People who choose not to wear head coverings may find that they are more likely to be asked questions about their condition than those who wear wigs or hair pieces. However, AAAF does recommend all people with Alopecia Areata have a sunhat and sunblock when out in the elements in order to protect the delicate skin of the scalp, ears, neck and face from damage.



Other considerations

In addition to these methods of head covering or treatment, there are measures that can be taken to minimise any negative effects of hair loss, particularly relating to loss of eyelashes and nasal hair.

- Sunscreens are important for the scalp, face, and all exposed areas.
- Glasses or sunglasses protect the eyes from excessive sun and from dust and debris when brows or lashes are missing.
- Wigs, caps, or scarves protect the scalp from the sun and keep the head warm.
- Ointments or saline spray can be applied inside the nostrils keeps them moisturized and help protect against dust or particles invading the nose when nostril hair is missing.

Support for Your Family

AAAF has a variety of resources available designed specifically to assist the entire family in their journey with the Alopecia Areata. Which options work best for you will depend on the age and personality of the child with alopecia, and your family's individual situation. Further information about all resources listed here can be accessed via our website: www.aaaf.org.au

Registry

By registering with AAAF, we can keep you up to date with the latest research, events and programs in your area. We strongly recommend registering via our website as it is the best way to stay in the loop about anything new.

Video Resources:

"Alopecia Areata: Why Does My Hair Fall Out?" was created by the AAAF as a resource for children, their families, friends and schools to help understand and explain Alopecia. It is aimed at 4-12 year olds and contains information about what the condition is and how to manage it. It also includes interviews with several children with Alopecia and their experiences with the condition. It is available in DVD format or online.



For older children and teens, we also have a series of videos discussing some of the emotional issues that come with Alopecia Areata, such as telling friends about the condition and coping strategies, and a series on styling, including makeup tips, information about wigs and how to tie headscarves. Again, these are available as a DVD from our e-store, or online.

Support Ambassadors and Branch Managers

AAAF Support Ambassadors assist the Foundation by actively promoting and creating awareness about the condition. All have personal experience in living with Alopecia and can be contacted directly for one-on-one support, along with hosting information sessions about Alopecia at schools, clubs and youth groups.

AAAF has Branch Managers in most states. These are all individuals who have experienced Alopecia Areata themselves, or are a parent supporting a child with the condition. They are the first port of call for people with Alopecia Areata in their state and can provide assistance and answer inquiries. Branch Managers also coordinate events in their state on behalf of AAAF and are a great way to get in touch with other people who are in the same situation as you.



Support Groups

One of the most beneficial things you can do for children with alopecia is remind them they are not alone. The AAAF has branches in most Australian states and local online forums which you can connect to. As a parent, you can use these groups to connect with other parents within your local area to organise meet ups or

playdates, or share advice and stories. For teens and young adults, the groups are a great way to make friends with other people with the condition and provide a supportive environment to share any questions or concerns they may have with people who have been through the same experiences.

Brochures

AAAF has a range of brochures about Alopecia Areata which can be provided in hard copy or accessed via our website.

- Teens talking about Alopecia Areata,
- Coping with Alopecia Areata
- The grieving process that can accompany hair loss
- Parents talking to parents
- General information.

Carly:

It's ok to grieve. It's a loss after all and it's natural to grieve. Take time to grieve and be good to yourself. Eat well. Rest.

School Pack

AAAF has created a School Pack designed to help teachers and educators introduce Alopecia Areata to the classroom. Developed with the help of child psychologists and early childhood educators, this pack includes lesson plans, advice from other parents, sample letters, and templates to use to inform school staff about Alopecia Areata.

The School Pack was designed with the belief that information, awareness and communication are the best tools for combatting bullying and ensuring a happy and healthy school experience.

Wigs For Kids

AAAF believes that the decision whether or not to wear a wig is a personal choice. As government assistance and Medicare / Private Health Care rebates are limited and vary across states, AAAF established the Wig for Kids Program to ensure that children wanting to wear a wig get the information, service and support needed.

Encourage your hairdresser, family and friends to support our Donate Hair Program. All funds raised go into supporting the Wigs For Kids program.

Events:

The AAAF holds many different events throughout the year. From trivia nights and Open Days, to causal catch ups and morning teas, we have something that will suit children and families of any age. You can find out about our events by registering, following us on Facebook, or checking out our website.



Greg:

My advice to parents is that no matter how you feel or what your fears are, it is important to remain positive. Children are more astute at picking up on this sort of stuff than we often give them credit for. So stay positive. Alopecia Areata will not stop anyone from achieving anything and it is important to not only believe this (because it is true), but do your best to make sure your child believes it too.

Our Stories

If you haven't heard of Alopecia Areata before your child is first diagnosed, it can feel like you're the only family in the world going through this. That is definitely not the case. Alopecia affects hundreds of thousands of families within Australia, and millions of people world-wide.

Here are several stories from other families and young people with alopecia sharing their journey with the condition.

Stella Horsley, 13

I got Alopecia Areata a few weeks before my seventh birthday. My hair simply came out in clumps, and in a few weeks, it was all gone.

I am now 13. I have some eyebrows and a few eyelashes, but the hair on my head has never come back.

When it all started, I was really scared and didn't know what was happening to me. Dad has Alopecia Universalis, so when I was diagnosed with Alopecia Areata, I knew what it was about.

I was very worried about getting bullied and teased because I now looked different from everyone else. I also really didn't like the way people stared at me all the time. This all got better, when I started to wear a wig. It was so good to go out and not have people stare at me so much, or have to explain Alopecia Areata all the time.

This year, I started high school. I was nervous about the fact that I would have to make new friends and tell them about my Alopecia. Mum, Dad and the school let me decide how I wanted to handle it. So to start with, I told a very small group of new friends before we went to camp. At the end of term two, even though I wear a wig, I decided I needed to tell more people. My teacher set aside time for me to tell my class. I played a video, did a presentation and answered questions. It was really nerve-wracking, but I felt a great sense of relief once everyone knew. My class was really supportive and now they understand what Alopecia Areata is and what I have to live with on a day-to-day basis. Hopefully, they will just accept it as a part of me.



To anyone going through something similar like me, the main piece of advice I can give is to encourage you to just be yourself and don't be afraid to open up to your friends and family. Tell them how are feeling because they will be able to help and support you.

Erin, Stella's Mum

It was the most scary and heartbreaking thing to witness. Stella's Dad, Andrew, was brushing her hair one morning and her hair just came away in clumps. Andrew looked at me and we exchanged no words, just a heartbreaking silence of fear and worry that something awful was happening to our child. It was so sad to see how different it made her look, every day the hair came away – it made our formerly robust and healthy girl look like she was unwell.

Stella's Dad has Alopecia Universalis, which started when he was 15 years old. So we already knew a lot about the condition; we knew it could be total and permanent like in Andrew's case. Even with that sitting very heavily on our minds, we tried to stay hopeful, that hers wouldn't be as bad as his experience. But we also knew that the earlier and more extreme it is, the more unlikely it was that her hair would ever come back. We also knew that it was unpredictable, with limited successful treatment options. It was hard not to feel utterly hopeless.



I always imagined it would have been worse for others who hadn't heard about the disease, because it is very frightening to lose your hair so quickly. Like most parents first faced with the disease, I was initially in shock. I couldn't believe that it was possible, desperately clinging on to the idea it would just stop. Then, both, Andrew and I felt incredibly guilty that we had passed this condition onto our daughter. Andrew felt really bad, but looking back we also know that Andrew having the condition made it more normal for Stella. She could see that the condition hadn't stopped her strong successful father and ultimately, she knows she can survive this challenge.

We also struggled with the way other people responded; losing one's hair really challenges our own ideas of beauty and vanity and as a society we are not good with dealing with it. Many would

quip 'it's only hair' but the reality was that each time someone said that with a healthy head of hair on their heads, it didn't allow us the space and time to talk about or grieve for Stella's loss. It also made me feel like I was vain and superficial to be upset that my child has lost her hair – which isn't at all who I am, yet it is a horrible way to be made to feel when you are coping with your child having Alopecia, and being really worried for them and their future. It also meant it was very hard for Stella to process her own loss. It took her 12 months, including four months with a psychologist before she would even look at herself in the mirror.

As her parents, we will probably always worry about the impact that Alopecia Areata will have on Stella's future and how people will treat her. Stella is now in her teenage years, when appearance and identity can be so important. This will be our next hurdle to get through. Meeting other children with Alopecia Areata and their parents through Australia Alopecia Areata Foundation (AAAF), has really helped us. I now feel we can get through this and have more hope for the future.

Andee and her daughter, Ellie

In December 2012, when Ellie was three, she returned from a weeklong visit at her Dads, when I noticed how thin her hair had become on the sides of her head. My heart sunk, I immediately knew what it was, as my younger sister had Alopecia Areata as a child.

I took Ellie to the local doctor straightaway. Even after explaining my family history, she simply said "It's just a growing phase, it's nothing to be alarmed about. She'll be fine, bring her back in six weeks". Not satisfied that I was being taken seriously, I talked about it with a work colleague who suggested that I get a second opinion through her doctor. I took Ellie to see the recommended doctor who confirmed my suspicions and diagnosed her with Alopecia Areata. That was ten days before Christmas.



By the following February, all of Ellie's hair had fallen out. By May, she lost her eyebrows, eyelashes

and all the hair on her arms and legs and her condition progressed to Alopecia Areata Universalis – loss of all hair. To an extent, in terms of what to expect, I was prepared because of my sister's experience with Alopecia. Nevertheless, it was still shocking and hugely distressing. We tried creams, ointments, tablets and diet changes, but Ellie's hair didn't return.

Even though Ellie was very young, she was aware of her hair loss and that something major was going on. To help her process everything we spent a lot of time with psychologists and psychiatrists, went to skin specialists and just tried to continue on as normally as we could.

Ellie is now seven years old. She wears lots of funky scarfs and hats. She loves her school and is generally doing well. However, her journey with Alopecia certainly continues to have its ups and downs.

The reactions people have towards Ellie are very mixed. Many people think that she's been through cancer treatments – the looks can be of sympathy to almost "why do you have your sick child out in public". Sometimes the looks can be really hurtful and as Ellie is growing older she is becoming more aware of just how much people stare at her. I tell her to keep being brave.

Sadly, Ellie is also teased because of way she looks. She often asks me "why did it have to happen to me mummy?" It's heartbreaking ... all I can say to her is we love her no matter what and it's just made her extra special. As her parent, I need to remain strong for her and keep positive, even when it gets really tough. It makes me so proud to see her being strong and standing up for herself.

On the other hand, lots of people compliment Ellie on the various hats that she wears. She is always appreciative of their comments and will chat to them and tell them about her Alopecia. As a mum, it is empowering to see how brave your child can be at such a young age.

I really want Ellie to meet other children just like her, so we have been going to events for people with Alopecia and have joined online support groups. Ellie is slowly starting to make more and more friends, from as close to home as Brisbane to as far away as California – which isn't too bad for a seven year old!



I know we still have lots of challenges to face. I worry about how she will be treated by others as she gets older, especially during the teenage years when appearance and identity become more important. We have lots of girly chats about the positives of Alopecia – like not needing to shave and how by wearing wigs she can change her style whenever she wants!

My goal is to set Ellie on a path that helps to make her resilient and to see the positives of what can happen to us in life. I want her to challenge the value that society places on how we look. And I want her to know that, yes it will be sometimes tough, but I will always be there to support her. She really is one of the bravest little humans I know! My hope is that throughout her life she can embrace who she is, including her Alopecia and sparkle like the bright star she is.

Do I have any advice for parents of children that may be different? I say always tell your child just how special they are. I think we all need to remind ourselves that everyone is different in some shape or form. If we were all the same what a boring world we would live in! Every child is unique, some children will have more obstacles to go through than others, it's our role as their parents to prepare them to get through challenging times and grow as a person into adulthood. On a final note, try not to take the, sometimes judgmental, stares to heart, just remember that it's human nature to stare when things are different.



Alison and her son, Alex

I first noticed my Son Alex had a bald patch when he was 4. It was just a small circle on the side of his head. As his daddy has a shaved head I just assumed they had been experimenting with the clippers. A couple of weeks went by and I saw another bald patch but my husband and the clippers had nothing to do with it. Next step was a series of doctors, blood tests,

Paediatrician and then finally the Dermatologist at the Royal Children's Hospital in Melbourne. By this stage it was out of control and out of our control. Alex's hair was on the bed, pillows and especially in the bath. It was everywhere except on his head. We were totally shocked and confused as Alex seems so happy and healthy. I remember the Dermatologist gently tugged on a chunk of Alex's hair and it just came out in his fingers.

After a course of steroids all the hair grew back and our boy looked 'normal' again as per society's expectations. It wasn't to last! The next course of steroids failed to work and then we started to look at other drastic treatments such as medical Acetone and injections in his scalp to promote hair growth. We joined the AAAF and I began to do more research and ask more questions. The biggest thing that jumped out at me was that sufferers of Alopecia were saying certain treatments were terribly traumatic and can cause physiological damage more so than the actual Alopecia itself!

We armed Alex, age 6, with all the information, good and bad. We felt that with our support, it was up to him to choose the next course of action. We did not want to keep him in the dark although we did want so much to protect him from the stares, comments and questions. By now the stares were part of everyday life for him. Alex seemed rather oblivious to it but I, his mother, would just cringe inside. Then there were the never ending questions: - "Are you dying"? "Do you have cancer"? "Why don't you have any hair"? We would have paid thousands of dollars to purchase Alex a wig but he chooses not to wear a wig. He chooses not to wear a hat and he chooses not to have any further treatment!

We have had some counselling sessions but this year something changed. Alex has Alopecia and has accepted it. Now his attitude and outlook have changed. Through acceptance the comments and questions have declined or maybe they just don't bother him as much. Alex doesn't want to hide and why should he? Embracing Alopecia rather than fighting it has been the best outcome for Alex and our family. Through the AAAF we have met some truly wonderful, encouraging and supportive people. We attend social activities as a family and as a couple. It has opened the door to us and more recently Alex appeared in a Uni Project - TV commercial based on Alopecia and he thoroughly enjoyed being the star of the show! Alex chooses to make the most out of Alopecia and doesn't hold back on anything in fact quite the opposite. It doesn't have to be a battle! We have a resilient, positive, strong willed young man. He may not have hair but he is healthy, wealthy and wise otherwise in his life – That's the greatest gift of all!

My lasting comment, I asked Alex "What he thinks about Alopecia". His response..."I love it! I get to go ice skating, go on You Tube and TV."

Community Q&A



?

If you could go back to when you had just been diagnosed with alopecia, what is the one piece of advice you would give yourself?

If you could go back to when you had just been diagnosed with alopecia, what is the one piece of advice you would give yourself?

Jayne: Do not be hard on yourself. Allow yourself to be sad or a little bit low on occasions. This is normal and natural, but always pick yourself back up and fight the fight. You can do it.

Stacey: Just to let them know that they are special & nothing is wrong with them. Just different and more caring. Most important is to remind them they are strong & to not let the bullies of today get to you.

Alicia: This is part of you now. Embrace it and never feel ashamed.

Rhyannon: No hair, no care! Hair does not define the person you are - let your personality shine through! You are you. Rock it!

Michelle: As a parent, I would say go through whatever you need to accept it, try things, research and then find peace with it. Always be open and tell as many people as you can, as it feels like your educating people one by one. Never shy away from it - It is what it is. It's stopped my boy Charlie from doing absolutely nothing and it never will!

Kate: Regardless of how you feel, treat yourself like you are royalty. You're different than everyone else which makes you special, not weird. Honour that, do not feel sorry for yourself - you have something different to offer the world.

What is the one thing you wish you'd known when you or your family member was first diagnosed with alopecia?

Sabine: That the AAAF existed

Rachel: That it's not the end of the world, and that you're not alone

Ruth: Wish I'd genuinely understood that it was going to be ok.



?

What is the one thing you wish you'd known when you or your family member was first diagnosed with alopecia?

Michelle: I didn't realise how unpredictable it was, when my daughter was diagnosed. I spent a good year obsessing over a pattern that associated with hair growth and hair loss.

Katie: Other people with kids our little boys age so we could meet up and talk with others in the same boat at the same time, and also for our little man to see himself in another little person.

Stacey: Just more. More information. When diagnosed, the doctors should give help line numbers or group contacts so when questions rise you can get information from another person in similar circumstances

What is the one thing you are most grateful for on your journey with alopecia?



Luke: The support of friends and family.

Heidi: As a teen going through alopecia I was grateful that my parents never chose on my behalf. They let me make the final decision on treatments, shaving my head, the choice to wear hats/scarves/wigs. It made me feel like I had more control over what I was going through.

Alicia: friends at school who protected me from the bullies and never having to shave my legs!

Shea: Having amazing support around me and having a sense of humour!

Rachel: The new perspective on life

Bianca: Working my self-love muscle! Each day I wake and go to bed at night I'm practising self-love and acceptance. Nothing else in my 41 years of life has had me work at anything so persistently.

Hannah: Overwhelmingly grateful for the support of my family and friends, their love, encouragement and sense of humour have got me through the good and bad days.

School and Bullying

School can be a complicated time for children with Alopecia Areata. For this reason, AAAF has created a School Pack, designed to help parents and teachers to introduce Alopecia Areata to the classroom which is available on the AAAF website. For further information about managing the schooling period, consult the School Pack.

Eva:

Stay strong, stay positive, get on with life. You are not sick, you can do anything you dream of.

For young people with Alopecia Areata, bullying can be a concern. It is also common for other children to mention the hair loss, point it out or ask invasive questions about it. This can feel very uncomfortable for the child with alopecia, but many children who engage in these behaviours do so simply because they don't understand what the condition is. If your child reports being bullied due to their condition, it is important to ascertain exactly what happened and whether it was truly bullying behaviour, or simply ignorance. This will affect how you will want to manage the situation. Serious, consistent, or physical bullying should always be reported to staff, and lack of understanding of the condition can be dealt with through information and awareness.

Spread awareness about Alopecia

Spreading awareness about alopecia can be done in many ways. You could ask the school about hosting an information session at an assembly or in class. You could write a letter home to the children's parents, ask the teacher to show a video in class about alopecia, or conduct one of the Alopecia Areata themed Lesson Plans which can be found in AAAF's School Pack.



Write a letter to go into your school's information for casual or substitute teachers.

Most schools have an information pack which they hand out to new or visiting teachers. These information packs include things like emergency plans, the school's rules and codes of conduct, and information about children with severe allergies, so that teachers can be prepared for any eventuality.

Many people with Alopecia Areata have had negative experiences with new school staff who are unaware of the situation. Often these are just small misunderstandings, such as asking a child to remove their hat in class, but can feel very serious to the child. Ask your school if you could include a letter for substitute or casual teachers, to let them know what the situation is and any special rules that may apply to your child. A template for such a letter can be found in AAAF's School Pack.

It's likely that at some point another student or perhaps a teacher will ask your child about their condition. Even if the person asking is only expressing innocent curiosity, being asked about their hair loss can feel confronting and distressing for many young people with Alopecia Areata.

Chelsea: *Remember that being bald is beautiful. Don't let what others say bring you down as you are ten times stronger than them.*

Inform teachers and principals about the situation and how they can help support your child

Making sure your child's teacher/s and principal understands what Alopecia Areata is and how your family is managing the condition is hugely important. Even if your child doesn't want to tell anyone about the condition, they may require special permission to keep their hats on in class, or other concessions which will be much easier to gain if the faculty is made aware of the situation. Having teachers understand what is going on will also make it much easier for the teacher to prevent bullying within the classroom and playground.



Role play responses

Sometimes classmates and even other adults may ask your child about their condition or their sibling's condition, this is particularly seen when the sibling is older than the child with Alopecia. Each member in the family unit should feel comfortable talking about Alopecia. A good way is to role play scenarios. This does take some rehearsing and the child with Alopecia should be included and feel comfortable with the responses, more confident, and make the interaction less distressing. Responses can range from "It's called Alopecia Areata. It affects their hair and they are perfectly healthy." to "That is none of your business", "You can't catch it and it doesn't hurt me at all". What kind of response is appropriate will depend on the age of the child and their personality.

Chel:

Regardless of the child's age, they should feel in control of how they want to talk about their hair loss. Each year brings on new challenges and asking "how would you like to handle your Alopecia this year" should be a continuous conversation throughout schooling.

Siblings of Children with Alopecia Areata

When a child is diagnosed with Alopecia Areata, it affects the whole family. Siblings can go through a wide range of emotions that can affect their attitudes and experiences.

Siblings of children with Alopecia may feel some of the following:

- Protective of the child with Alopecia Areata
- Confusion about what is going on and why
- Anxious about developing the condition themselves
- Jealous of the attention the child with Alopecia Areata is getting
- Guilt that they do not have the condition ('Why them and not me?')
- Embarrassed or upset when people ask about the condition, or stare at and tease their sibling

Marcus:

Ensure your child understands what is happening, particularly highlighting that their sibling is still perfectly healthy and that Alopecia isn't something to fear.



Equal treatment.

It's important to be mindful of spending time and attention on siblings equally. Spending time with each child individually can help, as can encouraging involvement in activities like sport or the arts, where each child can shine and feel accomplished by their own merits.

Talking and listening.

Ensure your child knows they can always come to you and share their feelings and have them respected. Understand that they may sometimes express negative feelings like jealousy, anger or guilt about their sibling's condition and that this is normal. If you sense that these feelings are worsening or not going away with time and management, you may wish to seek support services such as a school counsellor or psychologist.

Children of Parents with Alopecia Areata

Parents who experience Alopecia Areata themselves can also have some unique challenges. As well as employing your own coping strategies to manage your alopecia in the way that you feel comfortable with, you will also need to decide how you will manage the condition as a family. As always, AAAF recommend information and explanation as the first steps to making sure everyone has a positive experience.

Your child may initially be frightened or concerned about what is happening and whether they will lose their hair too. It is also possible that your child or teenager will ask you to wear a wig or cover your head if you do not already do so. When this happens, it can often come as a surprise and feel distressing, but it is important to ask where the question is coming from. It could be that your child is being asked about your condition from their peers, or even that they want to try and protect you. Among adolescents, fears about wanting to fit in and appear “normal” can be a very real issue, and they may influence your child’s feelings about your alopecia.

There are a range of ways you can handle introducing your Alopecia Areata to your child’s peers. Some parents give their child the choice of whether or not they should wear head covering to a particular event or when being introduced to new groups of people, such as Welcome Days at a new school. It is important to keep in mind though that if you do not usually wear head coverings you may just be postponing questions about it until the next time they see you. Other parents choose to make the situation known immediately to other parents, teachers or school peers. How you choose to manage this is up to you.



If there are many repeated instances of peers asking your child about your Alopecia Areata, consider asking their teacher to read a book or letter about Alopecia to the class, host a question and answer session with the class, or write a letter to be sent to the parents of your child’s year group. AAAF can be contacted to help put together a classroom session explaining Alopecia Areata.

At some point, it is likely that your child will be asked, by their peers or other adults, about your condition. Preparing your child in advance is one of the best ways to ensure this is an easy and quickly forgotten experience.

Your child might need to answer the following:

- Why their parent has no hair?
- What causes it?
- Is it contagious?
- Is it related to cancer?

As with when dealing with children with Alopecia or their siblings, having knowledge of the condition is one of the best ways to help your child understand what is happening. Using an age appropriate explanation, help them understand what Alopecia Areata is and why it makes you look different.

Role playing responses is once again a very good technique. Discuss with your child what they might say if someone asked them why their parent looks different. Appropriate responses will vary depending on the child's age and your comfort level. Some options are "They have Alopecia Areata, but they are not sick", or "Their hair just doesn't grow". Most children will lose interest after receiving a response.



Q&A with Camille's daughters, Melody (14) and Juliette (10)

What's it like to have a mum with AA?

Melody: It's normal, except when we meet new people. It's difficult to explain it. If they're polite, they say nothing. So I tell them later "my mum has alopecia." "What's that?" "She lost all her hair, it's not dangerous, she's not going to die, it's rare" and they say "oh".

Juliette: sometimes they ask "will it grow back? Or does she have cancer?" I say no, she has alopecia. It's a disease where you lose your hair and it's very rare.

When is it hard to have a mum with Alopecia?

Melody: Sometimes in public, kids stare at her.

What does mum's Alopecia make you feel?

Juliette: Lucky, because I still have my hair.

What would you tell other kids whose mum has Alopecia?

Juliette: It doesn't matter. The Alopecia doesn't do anything.



Melody: it's gonna be difficult at first, but eventually people get used to it.

Juliette: If a kid laughs at you, tell them "it's not my fault, it's not her fault, so shut up".

What should kids tell their mum?

Juliette: Hug them and let them play with their hair.

Melody: I love you no matter how you look. It's not your fault, you were unlucky.

Do you like it better when mum wears a scarf, bandanna, beanie, hat, wig or nothing?

Melody: If my friends come over, I don't care. But at parent-teacher night, I prefer a wig.

Juliette: I like a beanie or wig. But not her purple wig, I like the brown ones.



The creation of this pack has been generously supported by The Vassie Dandanis Grant provided by the Genetic Support Network of Victoria.