

School Pack

Promoting
Alopecia Areata Awareness
in the
Primary School Classroom



AUSTRALIA ALOPECIA AREATA FOUNDATION INC

www.aaaf.org.au

Contents

What Is Alopecia Areata	3
A letter from the President	4
Things to know about raising a child with Alopecia Areata	5
Children and School	8
Self Esteem and Students	10
Help your child build self-confidence	13
Sample Lesson Plans	14
Ideas from other parents	18
School-wide awareness projects and fundraisers	20
Advice from parents for parents	21
Letter for new teachers	24
Sample letters	26
Siblings of Children with Alopecia Areata	29
Parents with Alopecia Areata	30
Support For You	31
Emergency Support	33

What Is Alopecia Areata:

Alopecia means hair loss and Areata means patchy.

Alopecia Areata is a condition which results in the loss of hair on the scalp and possibly other parts of the body. It usually starts with one or more small, round, smooth patches on the scalp and can progress to total body hair loss. It occurs in males and females of all ages, and often presents during childhood.

Alopecia Areata is a poorly understood disorder. We don't know exactly what causes it. There is a genetic predisposition and currently no cure. You can't "catch" Alopecia Areata; it is not contagious. It is likely that eventually the condition will be found to be "auto-immune", with another body tissue attacking the hair roots, causing the hair loss.

There are a couple of different forms of Alopecia:

- Alopecia Areata – smooth, round, bald patches of various sizes on the scalp
- Alopecia Areata Totalis – total loss of hair on the scalp
- Alopecia Areata Universalis – total hair loss on head and body

There is no physical pain or discomfort associated with the condition and it does not affect the overall health of the individual. Alopecia Areata is classed as a not uncommon disease, meaning that 1-2% of the population has experienced a form of Alopecia Areata. The course of Alopecia Areata is highly unpredictable; hair can spontaneously regrow even after years of extensive hair loss. It can (and often does) fall out again.

Although Alopecia Areata is not medically disabling, it can be very emotionally challenging and socially isolating. The emotional pain can be overcome with one's own inner resources and the support of others.



A Letter from the President

Dear Parents, Teachers and School Faculty,

As a parent of a child who is affected by Alopecia Areata, and having witnessed the lack of knowledge within our schools about Alopecia Areata, I thought it important to provide material to encourage our youngsters through some of the most challenging lessons in their life.

The Australia Alopecia Areata Foundation has put together this School Pack to ensure that families and schools have access to the resources that they need to help promote Alopecia Areata awareness in the classroom. It is our responsibility to provide this information to you as it will help enrich the curriculum of your school and serve as an aid in giving students with Alopecia Areata a positive and nurturing school experience.

In the classroom when teachers are planning their curriculum, meeting the individual needs of children can be challenging. When challenges are presented, it can be discouraging when resources are not readily available. The purpose of the School Pack is to provide useful information to help both teachers and parents, as it offers ideas about lesson plans, resources to read, as well as feedback and insight from other children, teachers and parents.

As you're planning, it is important to consider the level of openness and maturity of the students. Challenges for a child with Alopecia Areata do vary, so take into account what particular struggles they face; it is also important to let the child lead at a comfortable pace. You can implement discussions about Alopecia Areata, or self-esteem and differences, into the classrooms of students both younger and older than the child with Alopecia Areata; older students will serve as advocates for their younger classmate, and the younger students will use their innocence to ask important and poignant questions regarding Alopecia Areata. All the students will learn a valuable lesson in compassion.

I hope you use this valuable aid when planning your curriculum for a class with a student who has Alopecia Areata. I invite you to contact me with your personal experiences, or to request more insight information or feedback for this resource.

Sincerely,

Chel Campbell - President of AAAF



Things to Know About Raising a Child with Alopecia Areata

To Help Cope

There are many things you can do to help children manage with their Alopecia Areata.

Make sure they understand that it's okay to feel bad, or even cry. But they must always remember that negative feelings will pass.

If you find the child experiencing extended periods of negative behaviour or extreme mood and behavioural changes, it may be necessary to consider counselling.

Explain to your child that even though they have hair loss, they are not alone. There are many people, including children, with this condition. The AAAF can put you in contact with someone who has been through it.

Understand that the way you react to your child's Alopecia, will affect the way they react. If you are very stressed and upset around them because of it, chances are they will view their condition as something to be stressed and upset about.

Keep your child engaged in activities they enjoy. Whether this is sport, or the arts, or social groups, it's important for your child to have a strong sense of who they are outside of their hair loss. Keeping up with activities will help with confidence, build stronger connections with peers and build a strong sense of self. Be sure to inform organisers about the condition so that they can understand and assist. With some organisations, you may need to discuss adapting the rules, such as with ballet or gymnastics which have strict rules about hair styles.

Acceptance of Alopecia Areata will come at its own pace. A young child will go through many stages of acceptance as they mature. Be aware that even the most well-adjusted child may have a bad day or a bad encounter which throws them off. This is normal and it will pass.

Keep in mind that coping is not a black and white concept. Your child's journey will probably be quite variable, so it's okay for them to be dealing with quite well one week and then struggling the next. Don't consider these variations as setbacks, they're just a part of the journey.

Children with Alopecia Areata need to understand exactly what's going on in simple terms. Parents may think they're sparing the child by not discussing the problem, but in fact, they're probably creating much greater apprehension by avoiding open discussion.

Try to avoid statements like "it could be worse" and "at least it's not cancer". Although these statements are in many ways true, they do not help. If your child is distressed, phrases like this can make them feel guilty or that they don't have a right to feel as they do because others in the world have it worse than them. They may begin to internalize their feelings, and not want to tell you when they are unhappy.

Try to inform other adults in your child's life to not respond this way when discussing their Alopecia.

Instead of these statements, remind your child that no matter what is happening to their hair, they are still the same inside and just as valuable.

Teachers and parents need to remind other children that teasing and staring is inappropriate, unkind and unacceptable, and inform other teachers and children about Alopecia Areata.

On Being a Parent

My son has Alopecia Areata Universalis. At first he had mild, patchy Alopecia Areata, but it developed until he had no hair.

During the first few years after we received the diagnoses, we spent time seeing doctors, trying to figure out what the condition was and whether they could do something to make it better. One of the few treatments were cortisone injections on the scalp, which was supposed to suppress the immune system and stop the hair from being attacked. It made his hair grow back around the injection sites, but then other patches developed. We were fighting a losing battle.

At school, kids teased him. The school principal once wanted him to take off his hat to show respect at a funeral, but fortunately someone spoke up for him and said it wasn't necessary.

As he grew older and matured, I watched him gain self-confidence, within himself and with the condition. He appeared in the local newspaper and on TV as a spokesperson for people with Alopecia Areata. I'm so proud of him. He came a long way in dealing with not having hair.

I believe it's important for parents to feel that their child is okay just the way he or she is, hair or no hair. Children's opinions of themselves are shaped by how they think their parents feel about them. If parents even hint that their child is damaged or is not quite the way he or she should be, the child will adopt these same feelings.

Everyone is unique and different in some way. To feel that everything would be okay (or better) if only the hair would grow back sets up a possibility for long-term disappointment. If the hair grows back, it's wonderful, but you never know if it might fall out again. To count on something so unpredictable for self-esteem could be damaging.

At our support group we met quite a number of people with Alopecia Areata who had inspired us with their courage and humour in facing their condition and by making the best of it rather than letting it get the best of them.

Chel



Children & School

When children return to school, there's a lot of playing, yelling, running around, and lots of exciting new things to learn. A child who has Alopecia Areata may feel apprehensive about joining in the general excitement.

What can you do to support the child who has little or no hair, who must face the daunting challenge of coping with being noticeably different in a school environment?

Little Ones

Very young children often aren't as affected by having or not having hair. At this age they adjust more readily to whatever is going on. Hair does not have the significance and meaning that it does for older children or adult. Therefore how parents, siblings, teachers, childcare providers and other adults approach Alopecia Areata will make a big difference in influencing the child's perception of the condition.

As parents, you're dealing with other adults who make remarks, as well as your own feelings of pity, sorrow, guilt, and/or embarrassment that you take on for your child. However, try not to make the hair loss a major focus in the child's life, or a source of anxiety. Inform the caregiver about Alopecia areata and be open with other parents about the condition.

Early Primary

Early primary aged children face comments from peers, who are usually just curious. There are several things you can do to help with this, including speaking with teachers and the principal about the condition, getting a teacher to talk to school children about Alopecia, and arming your child with a few sentences that they can use to inform peers about Alopecia if they ask. The AAAF also has educational videos and Support Ambassadors who may be able to help.

There are many positive ways to provide support to children at this age, but the best support can come from the child themselves. A small child can relate in real terms the importance of having or not having hair has on them. Being informed on why they are different can make them feel important and special when explaining their hair loss.

A parent can't ignore a child's pain, but be careful that your desire to make things better for them doesn't become a shield for them to hide behind.

Give your child tools (love, support and strategies) and encourage them to stand up for themselves, and to make their own decisions about how to deal with situations. This will

greatly help them develop their own voice and resiliency, as well as better equip them to handle negative situations in the future.

Older Children and Teens

Beginning in the third grade, children become very aware of their appearance and they begin to judge themselves. This trait can be seen earlier for girls.

This reaches extremes in teen years when awareness and anxiety about physical appearance can be very strong. These are the painful years during which a young person either develops strength of character or refuses to rise to the challenge of accepting themselves for who they are.

A young person who has never worn head coverage in early childhood, may wish to wear head coverage in early teens, but then disregard head coverage again in late teens or vice versa.

There are many positive ways to provide support to young adults at this stage:

Always consult them about how he or she would like to handle the problem. Children and teens almost always have some idea about what would solve the problem. If possible, follow through with their desires. If not, it's important to explain why and help them seek alternatives.

Encourage them to take up activities in which they can excel. From sports to science fairs, your child will be able to find something they enjoy.

Encourage your child to receive support from class members, teachers, coaches, etc. This can be done by supporting open and honest communication and really listening when they need help. Encourage your child to combat teasing with honest and witty remarks (See page 11 for ideas).

Keep loving, accepting, talking and listening to how a child is thinking and feeling about him or herself. Your efforts will eventually pay off!

Self-Esteem and Students

Tips for Parents and Teachers

The school year can pose a particular problem for children who have Alopecia Areata. It is a time of life when school-age children and adolescents are especially sensitive about their appearance.

An individual's school experience can have a profound effect on the socialisation process. Since most children are unfamiliar with Alopecia Areata, many are uncomfortable with interactions. Teachers can help the child with Alopecia Areata to cope and can help peers to be sensitive and understanding.

How you feel about yourself is, in part, a reflection of how you think others view you. As children grow and develop a greater sense of who they are, it is important that acceptance and integration exist for them. There are various factors that shape and affect self-esteem:

- The respect, acceptance and concern of significant others: "Significant others" change from family members for the very young child, to teachers for the school-age child, to peers for the adolescent. Giving others the opportunity to ask questions and to voice their concerns develops empathy, understanding and ultimately, acceptance.
- A history of successes: By encouraging recognition of the positives, children can form a basis in reality for self-esteem. Children can be steered towards experiences that are likely to be successful, in order to enhance a positive feeling of self-worth.
- Values and aspirations: The more successes we have, the higher our aspirations and expectancies of what we can achieve. People who have overcome their physical limitations can provide positive role models. Encourage the child's expression of thoughts feelings and dreams.
- Problem solving: Teaching problem solving skills increases the likelihood that a child will feel a sense of control over life. Difficult situations can be viewed as learning experiences, rather than as a devaluation of self.

These ideas may be used as a starting point by parents and teachers inside the classroom and in the community. Most important is that the focus be creative and interactive. Remember that each child is an individual.

Adapted and reprinted with permission from *About Face*, Toronto, Ontario, Canada

Encourage Youngsters to Combat Teasing With Honesty & Wit

Statement from reader (8 years): Don't advise kids who are being teased in school to ignore it. It wrecks a kid's self-esteem. Kids call me names all the time and it hurts.

The best advice my mum was given from our counsellor was to explain to the person teasing me that I am sick. By simply saying that I am sick, the attitude of the child teasing me changes immediately, they become sympathetic. It is at this time, when they are friendlier I can explain why I have no hair. I simply say "I have a bug that eats my hair".

On the football field when I am teased, it's a bit different. Here I use witty remarks, like "you can't catch me because your hair's too long", or "I mark the ball in packs because my hair doesn't get in my eyes".

Statement from Georgia: I didn't get bullied too much during primary school. I was a very loud and confident child, which I think helped. In one encounter with the school bully, she yelled, "Look at Georgia's bald head" at me after class one day. I only yelled back, "Look at your fat mouth". She didn't bother me again.

Statement from Kylie: The one thing that my mother introduced, and which I believe helped my self-esteem was this:

Stand in front of the mirror and look yourself in the eye and say "I AM BEAUTIFUL, I AM GREAT."

This helped all of us cope. It feels quite strange to do initially, but it is very powerful.

Answer from Annie: Great advice. Clever retorts are much more effective than an angry or hurt response. It's not always so easy to do, but with practise, and coaching from sympathetic adults, every child can learn some kind of defence like this. Parents and teachers should be on the lookout for students who need this kind of help.

Strategies for Teachers to Use to Help Raise Student Self-Esteem

Adapted from *Teacher Talk*, Indiana University

- Use student names
- Have conversations with every student
- Provide multiple ways for students to be successful in your class
- Display student work
- Give each student a responsibility in the classroom
- Provide opportunities for student work to be judged by external audiences
- Take time to point out positive aspects of your students' work
- Never criticize a student's question
- Take time to help struggling students understand the material
- Try to get to know about the student's life outside of school
- Ask students about their other activities (eg. "How was the soccer game, Natalie?")
- Help students turn failure into positive learning experience
- Encourage students to take risks
- Provide opportunities for students to make their own decisions about certain aspects of your class
- Provide opportunities for students to work with each other
- Don't make assumptions about student behaviour
- Allow students to suffer the consequences of their behaviour – don't be overprotective
- Allow students to explore options in different situations
- Celebrate your students' achievements, no matter how small

Help Your Child Build Self-Confidence

Self-esteem is your child's passport to lifetime mental health and social happiness; it's the foundation of a child's well-being and the key to success as an adult. At all ages, how you feel about yourself affects how you act. Think about a time when you were feeling really good about yourself. You probably found it much easier to get along with others and feel good about them.

Self-image is how one perceives oneself

The child looks in the mirror and likes the person they see. They look inside themselves and are comfortable with the person seen and think of this self as being someone who can make things happen and who is worthy of love. Parents are the main source of a child's sense of self-worth.

Lack of a good self-image very often leads to behaviour problems

Most of the behavioural problems that are seen in counseling come from poor self-worth in parents as well as children. Why is one person a delight to be with, while another always seems to drag you down? How people value themselves, get along with others, perform at school, achieve at work, and relate in marriage, all stem from strength of their self-image.

Healthy self-worth doesn't mean being narcissistic or arrogant;

Self-worth is having a realistic understanding of one's strengths and weaknesses, having love and respect for yourself and knowing you are valuable as a person, no matter what. Because there is such a strong parallel between how a person feels about themselves and how a person acts, helping your child build self-confidence is vital to discipline.

Throughout life your child will be exposed to positive influences builders and negative influences breakers. Parents can expose their child to more builders and help him work through the breakers.



Sample Lesson Plans

Feeling Flashbacks

By: Bonnie

Grade Level: Primary

Overview: Here's a lesson that's good for visual, auditory, and kinesthetic learners. This lesson uses a cooperative learning structure called Mill and Mingle to help students share and express their feelings and to help build a sense of community.

Objective:

To share and express feelings

To build a sense of community in the classroom

Materials:

Flash cards of different feelings

Music player and music appropriate for grade level

Space to move around freely

Paper and pencil (or a journal)

Activities and Procedures: Mill and Mingle: While music plays, students circulate through the classroom. When the teacher stops the music, the students form pairs by turning to the person closest to them. The teacher calls out a feeling (showing the students a flash card, a cue for the visual learner) and the pair shares with each other a time when they have felt that feeling. The music starts and the students mill and mingle again. The process is repeated several times.

Possible feelings: Happy, angry, embarrassed, lazy, scared, frustrated, shocked, loved, proud, important, curious, pleased, bored, disappointed, upset, joyful, sad, surprised, terrific, alienated, ashamed, worried.

Note: It is very important that the teacher select what feelings are to be shared and to discuss and model them in the classroom prior to beginning the lesson.

Tying it all together: Ask the students to identify similarities and differences in the feelings that they shared.

Journals: Ask the students to write down either on a piece of paper, or in their journals, about their experience of sharing feelings.

Who I Am Collage

By: Linda

Grade Level: Primary

Overview: It is surprising the range of knowledge and interests our students have, especially when we take the time to talk to them and learn about them. This activity gives students a chance to reflect on who they are and then to share that information in a fun way with their classmates.

Purpose: In order for students to build self-esteem, they need to know who they are and what is important and unique about themselves. They also need to have a safe and supportive environment where they can express what they feel about themselves. Students can become resident “experts” in the classroom on their different hobbies. This lesson is one way of finding out what the range of knowledge is among a group of students.

Objective:

Students will use an appropriate way to share facts about themselves.

Students will become aware that they and their classmates are unique. Students will describe orally to a group of peers who they are.

Students will find pictures or phrases to symbolize components of their personalities and interests.

Resources:

2 or 3 magazines per student on many areas of interest

Construction paper, assorted colours

Glue

Scissors

Activities: Students will cut pictures or word phrases out of magazines that represent their personal interests and abilities. The pictures and words are glued onto a large sheet of construction paper to form a collage. The completed collages will be displayed and numbered.

Without discussion students are given time to write down who they think each collage belongs to.

Tying it all together: Each collage is identified by its owner, who will then be allowed to explain what the symbols stand for. Students love this activity. They also like the collages to be displayed for a couple of weeks and from time to time they will make comments about things

they should have included or should have been included on a classmate's collage. Students love to find out about each other. They also love when a teacher creates a collage too!

Who I Am Scrap Book

By: Anna

Grade Level Primary

Overview: It is surprising the range of knowledge and interests our students have, especially when we take the time to talk to them and learn about them. This activity gives students a chance to reflect on who they are outside of school and to share their life styles with their classmates. Students take a teddy bear home to participate in their day to day life over a week.

Purpose: In order for students to build self-esteem they need to know who they are, what they have in common with others, how they differ and what is important about themselves personally. Students enjoy laughing at silly things that other students do, and laughter breaks down many barriers. This lesson allows the students to explore their own uniqueness in a safe environment at home, but then be able to share this with their classmates.

Objective:

Students will become aware of the uniqueness of themselves and of others. Students will describe orally to a group of peers who they are.

Students will find pictures or phrases to symbolize concepts of their personalities.

Resources:

Scrapbook – large enough to cater for 1 page for each student in the classroom

Teddy Bear

Glue, scissors

Activities: Each student takes the bear home for a week, starting on a Tuesday, and takes photos of the bear interacting with the student in day to day activities. These photos are printed and placed in the scrap books with words explaining the activity being done and how bear enjoyed the activity.

Tying it all together: As students taking the book home each week, the scrap book grows full of different experiences. On Monday the student returns the book and shows the weekly

experience that the bear has played in. The teacher can also go through the book and look for similar experiences amongst peers. Students love to find out about each other.



Word Search

Grade Level: Primary

Overview: This activity is a gentle way to introduce words and terms associated with Alopecia. Here the students can talk with each other while finding the words and open up discussion on what the words mean. It can help students to express and share their feelings.

Objective:

To share and express feelings

To build positive feelings on differences in the classroom

Materials:

Copies of the Word Search

A pencil.

Activities: Each student is given a word search and asked to find the words listed below. As the students are finding the word, the teacher should encourage conversation around the words.

Examples are: "What makes a person HAPPY?" "Does everyone have FEELINGS?" "How do you know if you are HEALTHY?" "Do you know someone with no HAIR?" "Do you know some words that explain having no hair? ALOPECIA BALD, TOTALIS, UNIVERSALIS".

Tying it all together:

Ask the students to identify differences in the feelings that they shared. Word search for printing and answer key can be found at the end of this document.

Ideas from Other Parents

Included in this section are great ideas from parents of children with Alopecia Areata. These ideas are 'tried and true.' They have been generalized so they can be readily adapted into your child/students lessons.

Idea #1

Talk to School Faculty in Advance about Wearing Hats

One of the teachers suggested that my son be allowed to wear a hat all day in school. The administrator agreed, so I called all the teachers and told them the new plan. That way, he would not get into trouble. What a difference! None of the teachers called attention to John because of it, and he wears a hat every day. He has two or three hats he likes and wears them on different days. His friends think it is very cool! He is much more comfortable!

Note: Talking to all his teachers and the school administration was the key to making it work. They discussed it as a group at their staff meeting and established a process to inform replacement teachers, so everyone was 'on the same page'. - Deb



Idea #2

Scarf Pass

Before my daughter began wearing her wig, she wore scarves. After getting special permission from the school she was made a "Scarf pass" pin that she wore to school every day. If anyone questioned her about wearing a scarf and breaking the rules, she would show them her scarf pass. No words had to be spoken. No adults questioned the scarf pass. - Diane

Idea #3

Role Play

Children are going to get teased and role playing with your child is a good way to prepare them for when this occurs. Discuss with the school about how teasing can be dealt with appropriate responses..

I would role play with my daughter and pretend she was one of the children doing the teasing. I worked with her to come up with suitable responses on what to say. One thing that worked

for my daughter was to put her hands on her hips, look them in the eye and say 'so what if I am bald', 'tell me something I don't know'. - Joanne

Idea #4

Show & Tell

My daughter had mentioned to us that some children in her class were questioning her about her 'bald spots'. There was some teasing from students. She decided to tell her teacher about her condition and asked if she could have a show & tell about her Alopecia. We prepared a poster on the positive and negative things about Alopecia Areata using her own words and she drew a self-portrait. I also prepared a letter to give to the parents of the children in her class to let them know what the show & tell was about. On show & tell day, our family came to the school and helped Caitlin with her presentation in front of thirty children. The children watched the video and then we talked about Alopecia Areata and how it makes Caitlin feel. The children asked some very good questions and Caitlin was a STAR that day! It is so true that when children understand something, they are less likely to tease another child. The posters we made that day still hang in the classroom. - Shannon

Idea #5

"Alopecia Areata: Why Does My Hair Fall Out?" Presentation

We showed a video about Alopecia Areata to all the children in my daughter's school. She was given the choice as to whether I would be present or not. She chose for me NOT to be there, and did it with the assistance of the school nurse, principal, and the school counsellor. This was a good idea because they felt that my presence may prevent the children from speaking their minds. - Elba



School-wide Awareness Projects & Fundraisers

Example #1

Crazy Hair Day

Ask the school if they can run a Crazy Hair Day. Flyers and information can be provided by AAAF. Suggest a gold coin donation to participate to raise funds that can be donated to Australia Alopecia Areata Foundation. Your school will receive a certificate of appreciation.

Example #2

Increase Awareness

Stephanie when diagnosed realized that there was not enough awareness of this disease and she decided to hold a fundraiser to increase awareness. She issued a challenge to the students and their families. This challenge was to raise \$500 and she would cut off her remaining hair. She asked the students to bring in their donations with their teacher's name on it. The teachers kept track of each student who donated. But the grand prize for all the students, if they met the challenge, was the principal had agreed to shave his head if \$1000.00 was reached. The students stepped up to the challenge and raised over \$3000.00.



Example #3

Festival of Kindness

Hold a 'Festival of Kindness' day. Students make hats to give away to people who would enjoy them. The hats can vary in style, colour and material depending on the age group.

Advice from Parents for Parents

Advice #1

Don't ignore the fact that your child has Alopecia Areata, like I did.

Ryan has had Alopecia Areata since he was 2 years of age. He is nonchalant about having Alopecia Areata and his attitude has rubbed off on our entire family.

When it came time for Ryan to go to school, our only concern was protecting Ryan from being teased. So my husband and I looked for a small school that had good moral teachings and small class sizes. We thought this was all that was needed in protecting Ryan from being teased. And in a way it did work.

Ryan was accepted into prep as a bald, confident boy with a lot of energy. He made friends quickly and was well liked. Some of the children asked Ryan straight away why he had no hair. Ryan simply told them that "a bug eats my hair before it grows", and the children were accepting of this immediately. Ryan no longer explains his condition. As the years have gone on, Ryan has remained with the same class group and not having any hair is no longer talked about – or so I thought.

Last week I was talking to some mothers, when out of the blue one mother said to me "when is Ryan's cancer going to get better"? Well this statement flawed me. I had no idea that people thought Ryan had cancer. But what was more devastating was Ryan's best friend's mother answered the question with "Ryan's treatment is none of your business". I just looked at her, "his treatment? What "treatment?" I said. "For his Leukaemia" was her response.

It occurred to me that day, that by protecting my son, I had actually done him a disservice. I needed to set the record straight.

At Ryan's school they have a junior school assembly each Monday. I asked the junior school principal if I could address the junior school and any parents wishing to attend to speak to them about Ryan's Alopecia Areata and recalled the story above to her.

I showed the children the video, "This Weird Thing That Makes My Hair Fall Out", and then answered any questions from the children and parents.

As new parents come to the school and inquire about Ryan's condition, I now have a group of other parents who can informatively speak on my behalf.

Chel

Advice #2

When my daughter Kylie was nearly 7, children had noticed the bald patches on the top and back of her head. I approached the school and asked to speak to the Grade 1 children (all three grades), to tell them about Alopecia Areata.

I spoke to each of the grades individually (when it suited the teachers) and told them what we knew about Alopecia, that it is a disease that attacks the hair, so that the hair doesn't grow.

The children were great and asked a lot of questions about how Alopecia worked and felt. I answered all the questions and since that time my daughter was never teased by children from that year level.

When I approached the principal, she also suggested she talk to Kylie and offer her an open door policy. The principal had said that Kylie could come to her room whenever she wanted to (if she was feeling uncomfortable, etc.) and not have to ask the office staff or anyone to see the principal, but just go straight into her office. Kylie never had to do this, but I think that the support that was there, was enough to give her strength.

Joanne

Advice #3

How Annie's Parents Prepared for the First Day of School

Annie and her parents put a lot of thought into how they would present a personally sensitive subject to their child's school. They would like to share with you their formula for success as they embarked on a comprehensive education campaign prior to the start of the school year.

- First, they contacted support groups for brochures and other material to better understand Alopecia Areata. It was also useful for us to have a supportive environment to rely on.
- Then, they met privately to discuss the situation with the school principal and with Annie's teacher.
- Then, they sent a letter and a copy of Annie's speech with a brief cover page from the principal to the school staff.
- The principal then held a meeting to explain the situation to the faculty and staff and to ask for their support.
- Finally, they sent the same letter to all the parents of students in her grade (copy of the letter available in this pack)

With all preparations in place, Annie and her mother gave their presentation with poise and self-confidence.

The results have been tremendous. Everywhere Annie goes in her school, all the children say, "Hi, Annie!" and include her in the day to day activities.

-Lisa



Letter for New Teachers

Most schools have some sort of information pack which they provide to new and casual or substitute teachers. Usually this includes copies of important school policies, emergency plans and sometimes information about students with special circumstances, like medical conditions or severe allergies.

Many children with alopecia find that new and substitute teachers can be unaware of their circumstances, and may accidentally cause distress or embarrassment by doing something like asking the child to remove their hat indoors.

The letter on the following page is a template which you can amend with details specific to your circumstances. You can then discuss with your schools administration about including it in their information pack for new and casual teachers.



Dear Teacher

This letter is to inform you of the special circumstances regarding _____ (Student Name) in class _____ (Class name or Year Group).

This student has a condition called Alopecia Areata.

Alopecia Areata is a medical condition resulting in hair loss in varying degrees to the scalp and body. It can present in many different ways, ranging from a few small, round bald patches on the scalp to complete baldness over the entire body – including eyebrows, eyelashes and even nose hair.

Alopecia Areata does no harm to the body and causes no pain or disability. It is believed to be an auto-immune condition, and is in no way related to cancer or cancer treatment. It is non-contagious, and can occur in both males and females of any age, although it often presents during childhood. Alopecia Areata is classed as a not uncommon disease, meaning that 1-2% of the population has experienced a form of Alopecia Areata. The course of Alopecia Areata is highly unpredictable; hair can spontaneously regrow even after years of extensive hair loss. It can (and often does) fall out again.

Though Alopecia does not cause any physical harm, it can be emotionally challenging and socially isolating. For this reason, we ask you to be aware of the student's circumstances. This student usually wears _____ (a wig/ a hat/a beanie/a scarf/no head covering) and they are allowed to wear this inside and during class. Please do not ask them to remove or explain their head covering.

We ask you to be aware of bullying, teasing or staring from other students, _____ (as there have been incidents of bullying/though we have not had any instances of bullying to date).

We also ask for sensitivity and discretion with this information. At this stage, the student's classmates _____ (do/do not) know about their alopecia. Please do not bring up the condition unless the student does first.

If you have any questions, please contact _____ (School principal/administrator/head teacher).

You can find more information about Alopecia Areata at www.aaaf.org.au

Thank you for your understanding.

Sample Letters from Parents

Example #1

Dear Parents,

Ryan has attended your school for 3 years and you may have noticed that Ryan has no hair.

Recently I have been receiving questions about Ryan's condition. Ryan has Alopecia Areata.

Alopecia Areata is a highly unpredictable, non-contagious, autoimmune disease resulting in the loss of hair on the scalp and elsewhere on the body. It has no other side effects.

I am holding a talk with the children at junior school assembly on..... This talk will go for approximately 15 minutes and has been scheduled to coincide with pick up times. It would be great to see you there.

Chel

Example #2

Dear Teachers and Staff,

Our son is starting just about to start school. He has been diagnosed with a disease called Alopecia Areata. Alopecia Areata is a highly unpredictable, non-contagious, autoimmune disease resulting in the loss of hair on the scalp and elsewhere on the body. The disease affects approximately 2 % of the population. The hair follicles remain alive, but in a hibernation like state with the possibility of hair re-growth at any time. Those who develop their Alopecia Areata in childhood usually have a poorer prognosis; this early-onset form is usually chronic and life-long. In recent research there has been verification that a patient's own T lymphocytes (a major class of white blood cells, which are a vital part of the immune system) attack the hair follicle and suppress hair growth.

In a physical sense, Alopecia Areata is not disabling; people with the condition are usually in excellent physical health. In an emotional sense, it can be challenging, if not devastating, especially for those with extensive hair loss. My son has been lucky so far to have a healthy self-esteem and to be accepted by friends without being ostracized. Hurtful remarks or comments, however, do upset him. This is where we would like to ask for your help!

Knowledge is power and by making Travis' school mates aware of his story, we believe that the teasing and harassment can be kept to a minimum. We would appreciate any help you can give in the education of others about Alopecia Areata. We would also like to know of any teasing of Travis so that we can help him deal with it.

Travis has already gone through all the treatments available and appropriate for him; there is no cure for Alopecia Areata. He currently is not on any treatment. He does wear a hat for both emotional comfort and protection from the elements. Please let Travis decide for himself if he needs to wear his hat or not. Please feel free to contact us with any questions, suggestions or comments.

Thank you for your help and support.

Jerry & Rhonda

Example #3

To the parents of all students

You and your family are probably as excited as we are about the start of school. Our daughter, Annie, will be attending in the first grade. She is eager for school to start, and looking forward to renewing friendships and making new friends. As her parents, we share her enthusiasm, but we also feel very anxious about a unique situation with Annie, and that's why we are writing to all the parents with children in first year.

As the result of Alopecia Areata, Annie has lost all of her hair, including her eyebrows and eyelashes (called Alopecia Universalis, described as the most severe form of Alopecia Areata). We would really appreciate it if you would take a few moments now to read this important letter and be sure to share this information with your family before school begins.

Although Annie has always been and continues to be quite healthy, she suddenly began losing her hair in January 1998. For over a year she has been completely without hair. She sometimes wears a wig, sometimes a cap, and sometimes she just goes "naked from the neck up," which can be visibly quite shocking, if you're not used to it.

Alopecia Areata is a poorly understood autoimmune disorder with a genetic predisposition and no cure. You can't "catch" Alopecia Areata; it is not contagious. When asked, Annie may describe her condition as "being allergic to her hair," which is a simplified if not a medically accurate description. Currently there is no effective treatment for Alopecia Areata.

Alopecia Areata affects both sexes, and all ages, but is most common in children. There is no pain or discomfort, and the overall health effect is benign. The course of Alopecia Areata is highly unpredictable; hair can spontaneously regrow even after years of extensive hair loss. It can (and often does) fall out again.

Although Alopecia Areata is not medically disabling, as you can imagine, it can be very challenging emotionally. The emotional pain can be overcome with one's own inner resources and the support of others. As you know, beginning around the age of six, children are

becoming much more concerned about how others view them, how they may differ from others, and whether others might be making fun of them. Since children at this age have become so aware of individual differences, they unfortunately can sometimes be disposed to poke fun at those who don't fit their definitions of "normal." One of the most frequent problems of teasing described by children with Alopecia Areata is having their wig or hat pulled off at school. Additionally, little girls wearing a cap are often mistaken for boys.

We really need your assistance and are asking you to discuss Annie's situation with your child, and to point out and emphasize standards of behaviour consistent with mutual respect.

Like all parents, we're eager to help make our child's school experience as positive and successful as possible. We hope you find this letter helpful in understanding her particular circumstance, and that it will help you talk with your child about it before school begins. We are aware that this will be a new and different situation for your child to grasp. Like any new behaviour pattern, it may need reinforcement throughout the school year and we hope we can count on all the families to understand this.

If we can answer any further questions, please don't hesitate to call us. In advance, thank you for your help and support.



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:

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

There are however many things that parents and teachers can do to help young people who have siblings with Alopecia Areata.

Age Appropriate Explanation.

Make sure the child understands what is happening. Alopecia Areata can be unpredictable and frightening for the whole family. Help to ensure your child understands what is happening, has an explanation that they can repeat and, particularly highlighting that their sibling is still perfectly healthy and that Alopecia isn't something to fear.

Roleplaying responses.

Sometimes classmates and even other adults may ask your child about their sibling's condition, particularly if they are older than the child with Alopecia. This can be stressful, confusing or upsetting.

One way you can help your child deal with this situation is to role play or rehearse what they would like to say in that situation. 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". What kind of response is appropriate will depend on the age of the child and their personality.



Equal treatment.

When the family and other significant adults begin to place a lot of focus on the hair loss, the child without alopecia may begin to grow jealous of the attention their sibling receives. It is therefore 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.

It's always important to actively engage with and listen to your children, but this can have extra significance in the case of conditions like Alopecia. Make sure your child knows they can always come to you and that they can 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.

Parents with Alopecia Areata

Being a parent with Alopecia Areata can have some unique challenges. One is the likelihood 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.

As with when dealing with children with Alopecia or their siblings, having an understanding 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.

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.

Support For You

Becoming Involved:

AAAF has many resources to assist children and their families with alopecia. We strongly recommend you register on our website so we can keep you up to date with the latest research, events and programs which may help and be of interest. Find out more:

<http://www.aaaf.org.au>

Contact a support group.

One of the greatest things you can do for children with alopecia is remind them they are not alone. The AAAF has branches in several states and many local support groups you can connect to. Find the support groups through the AAAF website: www.aaaf.org.au

"Alopecia Areata: Why Does My Hair Fall Out?" Video:

This video 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. Visit www.aaaf.org.au to find out more.

Support Ambassadors

AAAF Support Ambassadors are carefully selected from a cross section of the community (business, sport, politics, health, media) representing various age groups and states around Australia and all have lived with Alopecia Areata.

The Ambassadors assist the Foundation by actively promoting and creating awareness about the condition. They can be contacted directly for one-on-one support, and, wherever possible, can assist with information sessions about Alopecia at schools, clubs and youth groups. However, please be aware that all our Ambassadors are volunteers and physically attending events is subject to their availability and the date and location of the events.

Publications and Research

If you would like to gain a deeper understanding of the condition, or would like simplified information to provide to students and peers, you can find it on our website. The AAAF has funded many different research programs and created many brochures aimed at exploring and explaining Alopecia to different groups. The “Teens Talking to Teens” brochure may be particularly useful.

Attend an Event:

The AAAF holds many different events throughout the year. From Pizza Nights to Open Days 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

Wigs For Kids

AAAF believes that the decision whether to wear a wig or not 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.

Hold an event

The AAAF is committed to raising awareness about the condition, supporting people and families with condition and raising funds into research to eradicate the condition. In order to do this, we have many fundraising opportunities. Find out how you can be involved in fundraising on our website.

Emergency Support

For some young people, Alopecia Areata can be a very negative experience, especially when newly diagnosed. Instances of bullying, stress, anxiety and depression can be more common in people with Alopecia than the general population. The organisations below have many resources, support programs and help lines available for you to access.

Kids Help line

Kids and Parents Support Lines - Counsellors trained in knowing Alopecia Areata

<http://www.kidshelpline.com.au/>

(Ages 5 to 25 years)

1800 55 1800 (free call except from some mobile phones)

24 hours a day, 7 days a week

Headspace

National Youth Mental Health Foundation

<http://headspace.org.au/>

(Ages 12-25)

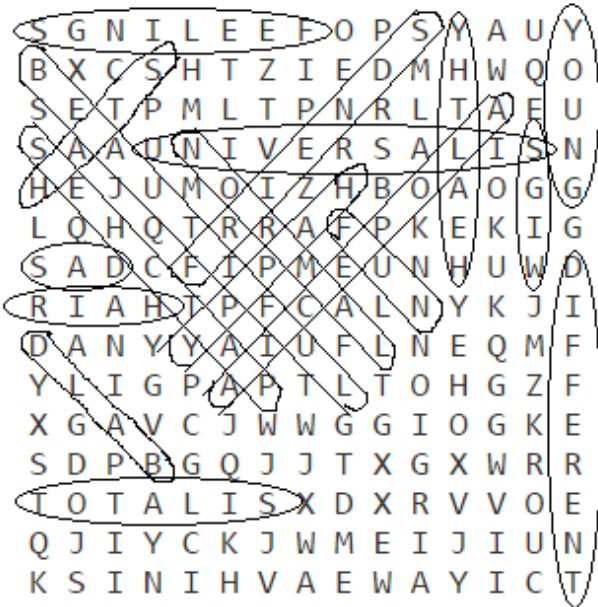
Emergency phone and online counselling available

Alopecia Word Search

S G N I L E E F O P S Y A U Y
B X C S H T Z I E D M H W Q O
S E T P M L T P N R L T A E U
S A A U N I V E R S A L I S N
H E J U M O I Z H B O A O G G
L Q H Q T R R A F P K E K I G
S A D C F I P M E U N H U W D
R I A H T P F C A L N Y K J I
D A N Y Y A I U F L N E Q M F
Y L I G P A P T L T O H G Z F
X G A V C J W W G G I O G K E
S D P B G Q J J T X G X W R R
T O T A L I S X D X R V V O E
Q J I Y C K J W M E I J I U N
K S I N I H V A E W A Y I C T

ALOPECIA
BALD
BEAUTIFUL
DIFFERENT
FEELINGS
FRIENDS
FUN
HAIR
HAPPY
HATS
HEALTHY
NORMAL
PATCHES
SAD
TOTALIS
UNIVERSALIS
WIGS
YOUNG

Alopecia Word Search



ALOPECIA
 BALD
 BEAUTIFUL
 DIFFERENT
 FEELINGS
 FRIENDS
 FUN
 HAIR
 HAPPY
 HATS
 HEALTHY
 NORMAL
 PATCHES
 SAD
 TOTALIS
 UNIVERSALIS
 WIGS
 YOUNG