

ALOPECIA AREATA GUIDE FOR PARENTS

Everyone copes with a disease like alopecia areata in different ways. The same thing goes for parents of children with alopecia areata. The sudden onset of the disease and the randomness of when and where hair is lost and may regrow can be frightening and challenging for everyone.

Some children develop alopecia areata at an early age, so it's all they know. Some begin losing their hair when they start school or as teens, times when they are trying to gain independence and discover who they are. As a parent, you are trying to learn how you feel about it, how you react to it, and how much support your child needs. You need to learn when to allow your child the freedom to figure things out on their own and when to step in. You also need to figure out if your child's behavior is due to hair loss or being at that stage of maturity. It can seem as if you are walking on a tightrope sometimes.

Aside from learning as much as possible about alopecia areata, you can do two other things to help your child manage their disease. The first one is to answer their questions honestly. This is important because they need to be able to trust you. Even a "white lie" can blow back on you. The other is to constantly affirm to your child that they are wonderful just the way they are. Alopecia areata does not define who your child is or the type of parent you are. It is a part of your child's life.

WHAT IS ALOPECIA AREATA?

Alopecia areata is a common skin disease. The word alopecia means bald, while areata means patchy. It can cause hair loss on just the scalp, or it can also affect the face, and other body areas, like under the arms or on the legs. People with alopecia areata often lose hair in circular, coin-sized patches on the scalp, but in more severe cases, they may lose all of their hair. It is an autoimmune disease, which means your body's immune system mistakes your healthy tissues as dangerous and begins attacking them.

Alopecia areata can affect anyone, regardless of age, race, ethnicity, or gender, but children are affected most often.

Alopecia areata in children 5 and younger

When children are pre-school age, they tend not to feel any impact of their hair loss yet. They are too busy exploring and learning about the world around them and gaining independence. They don't seem even to notice that they have alopecia areata. It may be interesting and other children may ask about it, but it doesn't take center stage in their life.

Older children with hair loss, from 6 to 12

Once children have started first grade, they begin to notice differences in people and they engage in new experiences. If they haven't yet, this is likely when the children start paying attention to what other people think and say about them. Other children may point them out or laugh – making the child feel self-conscious. An adult may make a comment that the child can hear.

Children with alopecia areata who feel good about themselves have an advantage when these things begin. Still, they could develop emotional or behavioral issues, especially if bullied. That said, if you've given your child a good foundation and they feel good about themselves, they have a better chance of staying strong if faced with difficult situations.

But, as your child gets older and enters the teen years, behavior and acceptance of the hair loss may take a sudden and sharp change – seemingly overnight in some cases. This is to be expected as they enter those often confusing teen years.

Teenagers have a lot to navigate

The teenage years can be a challenging time for both teens and adults in their lives. They are no longer young children, but they aren't adults yet. They are starting to think more introspectively, trying to identify who they are and where they fit in the world. They tend to analyze what they believe others are thinking about them.

Most teens desperately want to blend in, avoiding public criticism or ridicule. Teen girls are often very involved in making their hair "just right." But teen boys also do the same thing. They just may not be as obvious about it. For some teens, how their hair looks can make or break the day ahead. Understanding their need to feel good about themselves is essential. Stylish wigs or hairpieces can go a long way in boosting self-confidence.

Keeping teens busy in various activities can also help increase self-esteem and give them something – music, sports, clubs, etc. –they have some control over. It's important to keep in mind though, that some activities are harder on appearance than others. For example, a teen who chooses to wear a wig may have difficulty finding one that stays on during gymnastic routines or in a swimming pool.

PARENTS CAN HELP THEIR CHILD LIVE WITH ALOPECIA AREATA

Children, even teens, often take cues from their parents – although the teens will be unlikely to admit it! If your child sees you feeling sad, anxious, or angry about the alopecia areata, they may mimic your reactions, often internalizing them. If your child thinks you feel guilty, they may feel guilty themselves for putting you in that situation and end up in a cycle of self-blame.

Children are also quite resilient. They may take their situation in stride and cope quite well if they have support. It is also normal for children to feel sad or angry about their hair loss and these feelings shouldn't be ignored, even if they are usually happy and easygoing. The important thing is that they have support as they try to navigate the world around them.

Listen – listen to what your child says about their hair loss. Ask your older child if they want solutions or if they want to vent. Few things are more frustrating than a parent trying to solve a problem when the child wants to talk.

Talk to them about options – talk about the options available to them, such as head coverings, hairpieces, and so on. But don't push what you would do. Let your child decide and leave the option open that their decision is not permanent. They can change their mind.

SCHOOL AND ACTIVITIES – WHAT TO DO ABOUT THEM

The adults in your child's life should know about their condition unless they have specifically asked you not to. Teens may not want you to tell anyone, or they may want to do it themselves. But generally, teachers, coaches, and adults who spend time with your child should know and be educated on alopecia areata. They may need to step in if there are any problems with the other children or your child may want to talk to them, to have another person to confide in about their disease.

What to do about bullying

Unfortunately, bullying is a fact of life for some children. If your child is bullied because of their disease, it is important that your child know they are not alone. Here are some tips for you. Encourage your child to:

Tell an adult: Children are often afraid to tell an adult (teacher, coach, or some other person involved in the activity) because they fear the bullying will worsen. But bullying can't be dealt with if the adults don't know. This is *not* tattling. It is the right thing to do.

Stay in a group: If your child has a good group of friends, encourage them to stick together. Bullying is less likely when there are others around.

Stand up for yourself: Not everyone feels safe standing up to a bully, but sometimes it just takes "Stop it!" and calmly walking away. It could be that the "bully" isn't really a bully but is just trying it out to see what will happen. However, this is not an option if your child does not feel safe. Standing up for yourself is not bullying back though.

Block communications: If the bullying is online, your child needs to let you know so messages or apps can be blocked. Emails and messages can be printed out for proof if you need to go to someone in authority.

Don't let the bullies stop you from doing what you want. If your child enjoys swim club or playing soccer, they should continue to do so and not let the bully cause them to stop. This can be easier said than done, but your child needs to know that they deserve to be in activities and do what they love – alopecia areata or not.

Talk about it with your parents or trusted adults: Discussing the events can help clarify things and help your child put things into perspective. These conversations may also lead to potential solutions to bullying.

WHY SHOULD I BECOME INVOLVED WITH NAAF?

There is strength in numbers. NAAF is a grassroots, volunteer-driven organization that brings together millions of people from across the world, all of whom have one thing in common: alopecia areata. Join us in supporting each other, guiding research, and curing this disease. Your help is essential if NAAF is to achieve these goals.

Provide help for today and hope for tomorrow by:

- Reading stories from others, so you do not feel alone
- Sharing your own experiences
- Advocating for access and change at the local, state, and federal levels
- Getting or offering support
- <u>Donating to NAAF</u> to further its work in research and education

- Joining us for the annual Walk For Alopecia or create your own DIY fundraiser
- Receiving the monthly electronic newsletter and other communications
- Participating in webinars and other events listed on NAAF's website
- Attending NAAF's annual patient conference

Connect with us:

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