



COPING WITH ALOPECIA AREATA

YOU ARE NOT ALONE

It can be hard living with a disease like alopecia areata, especially if you feel alone. But you're not alone. Millions of people live with the disease. You may have met someone who has the disease and not even know it. Some people lose only small patches of hair, while others lose a significant amount or all of it. Many of the feelings you experience about having alopecia areata are shared by most others with the disease and those who love them.

But when you meet someone with the same disease, you will learn that you aren't alone after all. The National Alopecia Areata Foundation (NAAF) website (www.naaf.org) is a good resource for you and your family and friends. The information on the site introduces you to others who have the same diagnosis. Suddenly, there's a whole new group of people who do understand how you feel.

COMMON EMOTIONAL REACTIONS RELATED TO ALOPECIA AREATA

People with alopecia areata can have a whole range of emotions and feelings. Some may come and go; some may be constant. There is no right or wrong way to feel about the disease though. Your feelings are yours. Here are some of the most common reactions related to having alopecia areata:

- Feelings of being alone, or withdrawing and isolating yourself
- Loss and grief, mourning the loss of your hair and what it means to you
- Fears of your secret being discovered
- Sadness, depression, hopelessness
- Anger and embarrassment

- Guilt that you did something to cause this, or about how this affects family members

Parents may feel some of those, plus:

- Guilt that they passed on the disease
- Helplessness and sadness that they can't help their child or ease their pain

Other family members may feel shame, anger, or guilt too.

Another thing some people do is become too extreme in trying to find answers about why this happened and what can be done about it.

WHAT YOU CAN DO TO HELP YOURSELF

You probably weren't prepared when your doctor told you that you have alopecia areata. After all, unless you already knew someone with the disease, you probably never heard of it. Getting the news can start a cycle of negative or confusing thoughts and feelings. You might feel that you don't know where or how to start learning about alopecia areata.

Here are some suggestions:

- Gather information about alopecia areata from www.naaf.org.
- Learn about treatments, how they work, costs, and side effects. You can get information from NAAF, your dermatologist, and your pharmacist.
- Connect with others who also have alopecia areata.
- Think about whether you want treatment. You may want to talk to your doctor, family, friends, and others who have alopecia areata.
- Learn about the cosmetic things you can try. These include things like wigs and makeup.
- Learn how to manage symptoms of stress, depression, anger, or whatever confusing or negative emotion you feel.
- Talk to your family about how you feel about yourself.
- Continue to grow as a person, following your dreams in school, work, play, and relationships.

THE IMPORTANCE OF SUPPORT

Support is available in many ways, including one-on-one or support groups. It is important to have people in your life who understand what it's like to have alopecia areata.

NAAF has [support groups](#) throughout the world and many meet virtually. Attending one may help you see how it can help you. Support groups allow you to share your thoughts and feelings with people who can validate them. If there are no support groups in your area, you might want to consider starting one. You don't need experience to lead a group. Your role would be to provide a safe and confidential environment for people to share experiences.

These types of groups work for many people because they normalize the condition. The participants offer acceptance and understanding because they know what it's like to live with hair loss caused by alopecia areata. The others in the group can be good sources of advice, such as where to shop for wigs, how to find a good doctor, and more. They may also offer more hands-on things, teaching you how to put on a wig, wear a scarf, or even offer to take you to the doctor.

It also can feel good to offer support to others when you are ready to be the experienced one. Helping others can provide a sense of purpose and help you be less preoccupied with your worries.

However, not everyone likes being in a group. If you are uncomfortable with groups, one-on-one support can also be helpful. You can meet people at your doctor's office or through a support group first, chatting on your own later. You can also contact one of NAAF's [telephone support](#) volunteers for a conversation.

HOW TO IDENTIFY IF YOU NEED COUNSELING TOO

The idea of counseling or therapy can be scary, but it shouldn't be. Having a chronic disease can be traumatic. Many people with alopecia areata have a confusing set of emotions, ranging from loss to anger. Parents and other family members might also find they need counseling.

Mental health professionals are trained to help people with trauma. They can teach you tools to use when negative or confusing feelings surface. In addition, you can learn how to prevent them from surfacing in the first place. How can you tell if you need counseling? Think about how intensely alopecia areata affects your life.

Other signs might be if:

- Your feelings are overwhelming and your reactions are causing issues
- You're withdrawing from life and no longer participating in things you used to do
- You attend a support group and feel you need more help

Counseling gives you more time to focus on your own specific experiences in a safe and confidential environment. You might be more comfortable sharing issues here instead of in front of a group.

FINDING A MENTAL HEALTH CARE PROFESSIONAL

There are several ways you can find a therapist or counselor. You could:

- Ask your doctor's office for recommendations
- Ask people in your support group
- Contact your local mental health association
- Reach out to your insurance company

THE NAAF PATIENT CONFERENCE

Conferences aren't just for professionals. Every year, NAAF hosts the NAAF Patient Conference. It moves from city to city annually to reach as many people as possible. People from all over the world gather in a safe and encouraging environment. They can learn more about alopecia areata from top medical and research professionals, and others with the disease.

The conference is an excellent resource for people of all ages who have alopecia areata or love someone who does. The time spent at the conference allows them to make personal and emotional connections, some of which may turn into long-term friendships.

For more information on Support resources from NAAF, visit
www.naaf.org/find-support/

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
- [Donating to NAAF](#) 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:

National Alopecia Areata Foundation

65 Mitchell Blvd., Suite 200-B

San Rafael, CA 94903

www.naaf.org

Phone: 415-472-3780

Email: info@naaf.org



NAAF gratefully acknowledges the support for this informational brochure provided by:

