

How Do You Know You Are Not Alone?

Alopecia areata can be hard for those who have the disease and for their families. Although every experience is unique, there are some feelings commonly shared among those affected. For example, you might be thinking that no one knows or understands what you are going through. Many people with alopecia areata think this, and then feel relieved when they finally meet someone else with alopecia areata or learn of the National Alopecia Areata Foundation (NAAF). In addition to common thoughts and feelings about alopecia areata, there are also common emotional reactions to the disease.



What Are the Emotional Reactions to Alopecia Areata?

People who have alopecia areata and their family members often experience a variety of feelings and frustrations. Reactions to the disease can include feeling:

- Alone, withdrawn, and isolated
- Loss and grief
- Fear that others may find out you have the disease
- Fear that others may find out you wear a hairpiece
- Sadness and depression
- Hopelessness
- Anger
- Embarrassment
- Guilt or self-blame that you somehow brought the disease on yourself
- Guilt that the disease is affecting family members and loved ones
- Frantic in searching for an answer or cure (going to extremes)
- (For parents) Guilt that they may have genetically contributed to their child's disease
- (For parents) Helplessness that they cannot stop the disease or help ease their child's pain
- (For siblings and other family members) Shame and anger because the disease has also affected their lives



What Can You Do to Adapt to Your Alopecia Areata?

Most people are not prepared when they are told they have alopecia areata. For the most part, persons with alopecia areata, as well as family members and friends, are forced to deal with a variety of new emotions and experiences that can be confusing and unpredictable.

The suggestions below can help you deal with your alopecia areata:

- Gather information about alopecia areata from www.naaf.org, or call the NAAF office.
- Gather information about treatments, as well as their relative effectiveness, cost, and side effects.
- Connect with others who have alopecia areata through NAAF's support groups, telephone contacts, Pen Pal Program, website message boards, Facebook, Twitter or the Annual Patient Conference.
- Make decisions with physicians, family, and friends regarding whether to pursue treatments, and if so, which ones.
- Gather information from NAAF about prostheses (wigs) and cosmetics for dealing with hair loss.
- Preserve your emotional balance by learning how to manage symptoms of depression, anxiety, and stress.

- Strengthen relationships with family and friends who are willing to talk about feelings associated with dealing with alopecia areata.
- Pursue positive areas of your life (work, education, personal growth, exercise, health, recreation, intimate relationships, etc.).

What is the Importance of NAAF Support Groups?

NAAF has support groups throughout the world. If there is an alopecia areata support group in your area, it can be very helpful to attend. It is often beneficial to share your thoughts and feelings with others who have experienced many of the same things you have. If there is not a support group in your area, you may want to consider starting one. Absolutely no prior experience leading a group is necessary; you would simply be providing a safe and confidential environment to share experiences, including your own.

The healing power of support groups for people affected by alopecia areata is tremendous. Support groups work because they provide people with a sense of normalization, acceptance, and understanding. It is reassuring to see others who look like you and have similar experiences. People who have gone through the same thing are often the best sources of advice (where to shop for wigs, how to find a good doctor, etc.) and tangible support (rides to the doctor, styling a wig, etc.). It feels wonderful to finally be understood. It also feels wonderful to offer support to others who may be struggling with things that you have already gone through. Being helpful to others provides one with a sense of purpose. It also helps to become less preoccupied with one's own worries and concerns.



How Can the NAAF Patient Conference Help?

The NAAF International Patient Conference, a four-day event held annually in various cities, is for people of all ages who have alopecia areata or care about someone who has alopecia areata. People from all over the world who have alopecia areata and their families come together in a safe and encouraging place to learn more about the disease from the top medical and research providers, as well as other patients who have been in their shoes. The strength of the weekend helps you establish personal and emotional connections with others, which often results in long lasting friendships. Attendees frequently tell us of the positive effects the conference had on their lives, and we are more than happy to share this feedback with you.

How Do You Know if You Need Counseling?

For many people, alopecia areata is experienced as a trauma. The disease can also be traumatic for the parents and other family members of those who have the disease. Many people who have experienced trauma find it helpful to talk with a mental health professional who can help them work through their feelings and learn coping skills. A good way to know if you need counseling is to examine how alopecia areata is affecting your life.

Although experiencing the psychological reactions mentioned above is common, if your feelings are intense and overwhelming, or if your feelings and reactions aren't going away, counseling should be considered. If alopecia areata has caused a dramatic change in your lifestyle, for example, if you no longer participate in activities that used to bring joy to your life, if you are missing work or school frequently, or if you no longer feel you can talk or reach out to those who are close to you, you may need counseling.

We highly recommend alopecia areata support groups; often these groups alone provide sufficient help. However, counseling from a trained professional can be beneficial as well. Counseling gives you more time to focus on your own specific experiences and provides a safe environment in which you can share confidential matters. This will enable you to discuss issues that you may not want to discuss in front of a group.

How Do You Find a Mental Health Professional?

One way to find a mental health professional is by asking your physician for a referral. Another way is to call your local mental health association or crisis hotline and ask for a referral. Also, many healthcare plans provide information on local counselors. You might also want to ask a friend or fellow NAAF support group member who has been in counseling for a personal recommendation.



ALOPECIA AREATA



Helping You Cope



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