An iceberg floating in the ocean. The tip of the iceberg, which is visible above the water surface, is jagged and white. The much larger part of the iceberg is submerged below the water surface, appearing as a dark blue mass. This visual metaphor represents the concept of disease activity that is not always apparent from the surface.

Understanding Alopecia Areata (AA) Disease Activity... ABOVE and BELOW the Surface

A Planning Guide to
Help You Work With
Your Healthcare Team
to Optimize Disease
Management for AA

The information contained in this educational resource is intended to reinforce and supplement information you receive from your healthcare team. It is not a substitute for medical advice from your physician. If you have questions about the information you read in this educational resource, please discuss them with your healthcare provider.

This has been produced as a patient education resource by Pfizer Inc.

How to Use This Planning Guide

The Iceberg



Consider the popular phrase, *the tip of the iceberg*. This means that only part of an iceberg is visible above the surface of the water, yet below the surface lies a much larger piece of the iceberg that cannot be seen.¹ It is a commonly used image to help explain situations where what you see does not tell the full story.

The iceberg is a useful metaphor to explain what is happening in your body when you are living with **alopecia areata (AA)**, a complex autoimmune disease marked by hair loss, which can dramatically affect your life.^{2,3} That is because AA causes inflammation in your body that leads to hair loss and could lead to other potential medical conditions.^{4,5}

In the iceberg metaphor, *hair loss can be seen above the surface of the AA iceberg; the inflammation is what cannot be seen below the surface of the AA iceberg.*

This brochure is a different type of patient resource because it is designed to support *disease management decision-making*—the process of working with your healthcare team to set treatment strategies and goals focused on your medical needs.⁶

The medical content in this brochure is more in-depth than traditional patient education materials. That is by design. Each section explains important clinical concepts and raises key topics you may want to discuss with your dermatologist or other healthcare provider (HCP).

Disease Management Takeaway

If you are a patient, these new insights about AA may help you develop and manage an action plan for your condition through improved communication and shared decision-making with your dermatologist. If you are a caregiver, the information in this brochure may help you understand and support a patient in need.

What You Will Learn

Important things you should know about AA and your disease management. By using this guide, you will be able to:

- 1 Define AA and describe its common signs and symptoms
- 2 Understand the potential causes of AA and how it is diagnosed by your dermatologist
- 3 Describe how AA can affect your quality of life (QoL)—including the challenges that may affect you and your caregivers
- 4 Explain the other medical conditions that may develop with AA
- 5 Identify available disease management options for AA while understanding the core goals of AA treatment
- 6 Explain the importance of two-way communication between you and your HCP to support the AA disease management plan





Need-to-Know Information About AA

Understand these key facts about AA...then expand your understanding by completing some exercises to help you when discussing a disease management plan with your HCP.

1 AA is an autoimmune disease that may be chronic.

AA is a type of autoimmune disease that can be chronic.^{7,8} Autoimmune conditions are those where your immune system mistakenly attacks healthy tissue in your body.⁹ In AA, your immune system attacks hair follicles leading to hair loss and inflammation.^{4,8} That is why AA is also considered an inflammatory disease.¹⁰ The course of AA is unpredictable.^{7,8} Hair loss can happen once, or it can be chronic, which means a recurring condition that someone has long term.^{8,11} AA can be a relapsing-remitting disease, which means that a patient recovers before experiencing hair loss again at a later time.^{7,8}

Hair growth normally occurs in cycles: a phase of active hair growth, a transitional phase, and a resting phase before the hair is shed and the cycle begins again.¹² In AA, inflammation disrupts this cycle during the hair growth phase, and causes unexpected loss of growing hair. However, AA is “nonscarring,” which means that hair follicles are preserved, allowing the potential for hair regrowth (see “A Tip From the AA Iceberg” below).⁷

AA appears on the body in specific ways.⁸ The condition is marked by circular or oval patches of hair loss on the scalp, eyebrows, eyelashes, or other places where there is hair on the body.¹³ In most cases, hair loss is partial. But more serious cases of AA involve almost complete scalp hair loss; this is known as *alopecia totalis* (AT). Sometimes, AA leads to complete bodily hair loss—a situation known as *alopecia universalis* (AU).

Hair loss is only one physical sign of AA.⁸ People living with AA may also experience nail changes such as pitting and roughening of the nails. The medical term for this is *trachyonychia*.¹⁴ Nail changes occur in approximately 30% of all cases of AA and usually appear in more severe forms of the disease.⁸



A Tip From the AA Iceberg

During the diagnosis of AA, your healthcare provider may use the terms “nonscarring” and “scarring.” Nonscarring means that hair follicles have the potential for regrowth.¹⁵ Conversely, in scarring alopecias, follicles are destroyed and lead to permanent hair loss

2

The potential causes of AA and how it is diagnosed by your dermatologist.



The causes of AA are unknown.¹⁶ Some researchers have linked specific genes—or combinations of genes—that contribute to the development of AA.² (These are some of the same genes present in other autoimmune diseases such as type 1 diabetes and rheumatoid arthritis.) Environmental factors may also be at play.¹⁶ But what factors these are, and how they may lead to AA, is still unknown.



Your dermatologist diagnoses AA with a physical examination and a review of your clinical history.¹³ The physical exam specifically focuses on assessing nonscarring areas of hair loss for 2 defining traits of AA (See “A Tip From the AA Iceberg” on the previous page). The first trait is the appearance of *patches* of hair loss on the body.¹⁶ The second trait at the periphery of those patches, are hairs formed like exclamation points (short hairs that are thick at the top and thin at the bottom).



In some cases, AA may require more in-depth study.¹⁶ When AA appears on the skin in unusual ways, your dermatologist may recommend a biopsy or histological examination (eg, tissue studied under a microscope).

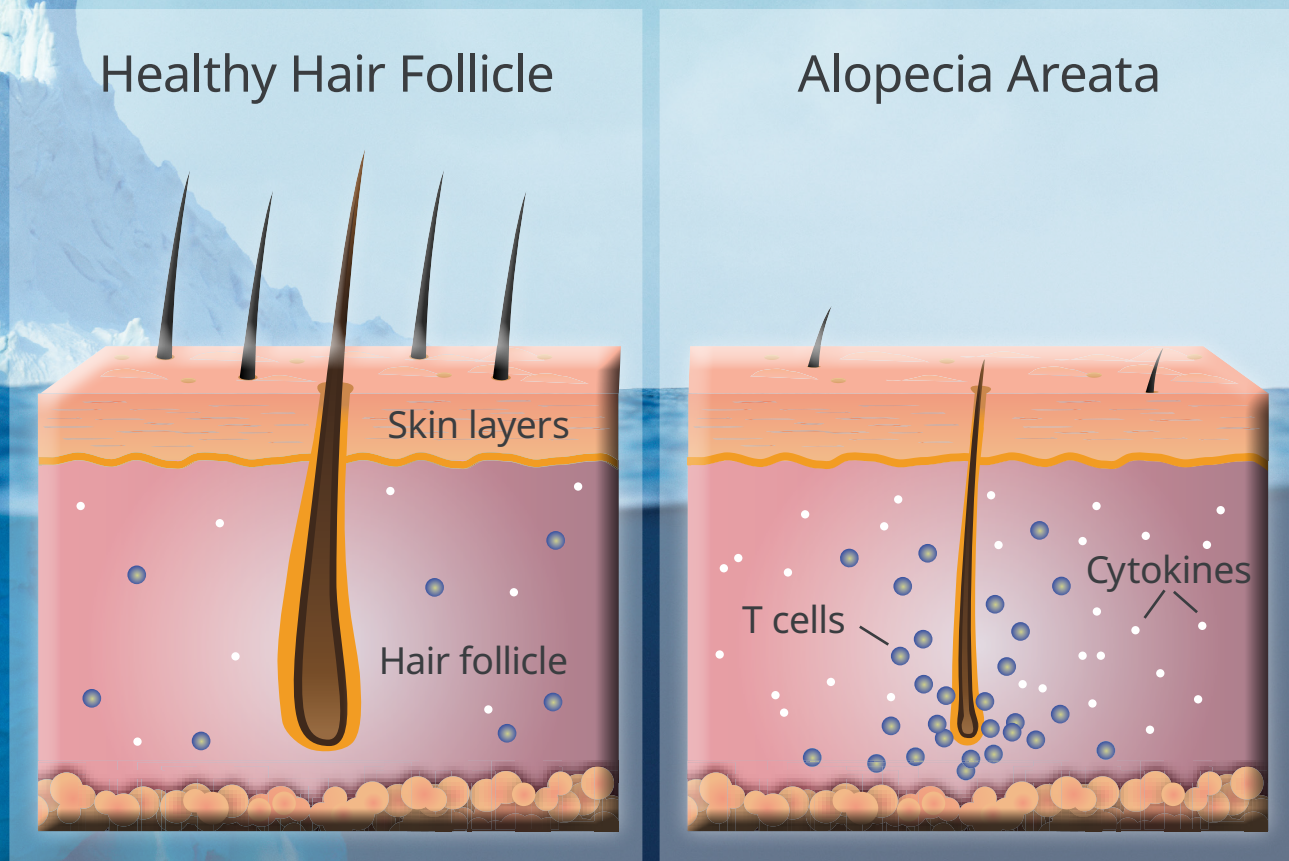


Once AA is diagnosed, your dermatologist will determine the severity of your disease. It is important to understand if the disease is mild, moderate, or severe because disease severity affects your treatment choices.¹⁷ Different severities of AA require different types of treatment.¹⁸ Not all doctors use the same criteria to determine disease severity.



A Tip From the AA Iceberg

Visible hair loss and nail changes are what can be seen above the surface of the AA iceberg. The inflammation is what lies below the surface of the AA iceberg and cannot be seen. Be sure to mention all hair loss and changes in your nails to your healthcare provider.



The iceberg metaphor helps explain what is happening above and below the surface of your skin when you have AA.

Underlying inflammation leads to hair loss as your immune system mistakenly attacks hair follicles.¹⁰

In clinical terms, *T cells*, blood cells that help your immune system fight infection, are activated and target the hair follicle.¹⁰

Additionally, *cytokines* (a type of protein) are secreted and contribute to inflammation.¹⁹

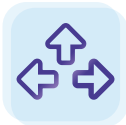


3 AA may affect the quality of life (QoL) for patients and caregivers.

AA may have a negative impact on your health-related QoL and emotional well-being.^{20,21}



Hair can be an important part of one's identity.^{22,23} So it can be distressing when there are dramatic changes in your appearance from hair loss.²³ Feelings of low self-esteem may result in and lead to social withdrawal.²¹



Research shows that AA affects virtually all aspects of a patient's life—notably, one's professional, educational, and romantic relationships.^{21,22}



The QoL challenges posed by AA do not only affect patients.²⁰ Family members and caregivers may also struggle with emotional issues as they strive to support loved ones under their care.



A Tip From the AA Iceberg

You should always keep your doctor informed about how AA is affecting your daily activities. Only by openly discussing lifestyle challenges can your doctor take steps that may help you.

4

Other medical conditions may develop when you are living with AA.

AA is associated with other medical conditions that are both physical and psychological.⁵ These are known as *comorbidities*.



Research has noted a link between AA and other atopic diseases such as allergic rhinitis (prevalence 26.5%), asthma (9.7%), and atopic dermatitis (also known as eczema, 7.9%).²⁴ Patients with AA may also have a higher risk of thyroid diseases (such as autoimmune thyroiditis, 41.4%), eye disorders (such as lens changes, 41.0%), and autoimmune disease (8.2%).



Psychological comorbidities are common among patients with AA.^{3,20} As discussed, AA may pose emotional challenges that include low self-esteem and social withdrawal.²¹

Recall the *inflammation* occurring under the surface of the AA iceberg. Stress may worsen it because increased levels of stress hormones in the body are thought to promote inflammation.²⁵



A Tip From the AA Iceberg

Some people may see AA as only a cosmetic condition.²² Because of this misinterpretation, it is easy to feel like you do not always get the understanding and support you need. Talk to your HCP for guidance and assistance.

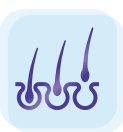




5

Disease management approaches for AA and the goals of treatment.

Unfortunately, there is no cure for AA and not all treatments work for everyone.²⁶ But there is encouraging news: new types of medications have been developed to support AA disease management.



AA affects people differently.¹³ The type of medication your HCP prescribes depends on the severity of your AA and individual factors such as age and medical history.^{13,26} Treatment approaches may vary. But the basic goals of AA disease management are the same: to decrease your immune system's attack on your hair follicles and enable hair regrowth.^{27,28}



Some patients with AA may only have one episode of hair loss.⁴ Other patients may lose and regrow hair more than once, in the same or different patches.⁷ Regrowth in one area may happen simultaneously with hair loss in another area. However, the potential for hair regrowth may be life-long since the disease does not destroy hair follicles. Once hair begins to grow back, hair strands can be thin and/or white at first, but usually return to their original thickness and color over time.



Current AA disease management approaches involve the use of oral, topical, or injectable treatments.¹³ Some treatments work at the cellular level to lessen inflammation and allow hair to regrow.



It was noted earlier that AA can be a chronic disease.⁵ Engage in ongoing discussions with your doctor about how long you should continue treatment. Any underlying inflammation remaining in your body needs to be controlled.⁴



A Tip From the AA Iceberg

Remember, AA medication can help to control the underlying inflammation in your body.²⁶



6

The importance of regular, two-way communication with your HCP team.

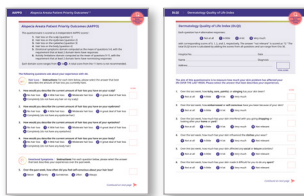
AA is difficult to live with.^{3,20} It may also be difficult to talk about because of the emotional burdens associated with the disease. Feelings of embarrassment and self-consciousness can occur in people with AA.²⁰



Keeping the lines of communication open with your HCP can help. When you speak honestly with your HCP, you can work together as a team to identify disease management areas of greatest concern.



Keeping your healthcare team aware of changes in your symptoms is important to ensure you're receiving optimal treatment. The Alopecia Areata Patient Priority Outcomes (AAPPO) scale²⁹⁻³¹ and the Dermatology Life Quality Index (DLQI)³² are 2 examples of standard questionnaires that can help you track information about the emotional and QoL effect of living with AA—important insights to share with your dermatologist. The AAPPO has 11 questions about hair loss, emotional symptoms, and activity limitations.²⁹⁻³¹ The DLQI is a dermatology questionnaire with 10 questions that assess how your AA has affected your life over the last week.³² Your responses provide important insights to help determine your disease management plan.



Copies of the ***Alopecia Areata Patient Priority Outcomes (AAPPO) scale*** and the ***Dermatology Life Quality Index (DLQI)*** can be downloaded at the Pfizer **personalempowermentportal.com** website. Once you complete the questionnaires, share the information with your dermatologist.

Discussion Guide Topics

Now that you have reviewed the key facts about AA, check your understanding by answering the following multiple choice questions:

1. AA is an autoimmune disease. What does that mean?

(Circle your answer)

- a. Your immune system mistakenly attacks healthy tissue¹³
- b. You may automatically get AA if it runs in your family
- c. You are immune from getting other diseases when you have AA

Say it in your own words...Why is it important to understand what type of disease AA is?

2. AA is also considered an inflammatory disease. What does that mean?

(Circle your answer)

- a. You will always get a fever when you have AA
- b. Underlying inflammation in your body contributes to hair loss⁴
- c. You will periodically get hot flashes

Say it in your own words...Why is it important to talk with your HCP before you consider not taking your prescribed medication when you have AA?

3. AA can be a chronic disease. What does that mean?

(Circle your answer)

- a. AA symptoms will disappear over time
- b. AA can result from contact with another person
- c. AA can be recurring and you may have it over the long term¹¹

Say it in your own words...What are some comorbidities associated with AA?

4. Besides hair loss, AA signs may also appear on what part of the body? (Circle your answer)

- a. The bottom of your feet
- b. Your nails⁸
- c. The folds of your knees or elbows

Say it in your own words...Why is it important to monitor your own AA signs and symptoms and discuss them with your healthcare team?

5. Patches of hair loss on the head tend to resemble what shape? (Circle your answer)

- a. Square
- b. Triangle
- c. Round or oval¹³

Say it in your own words...In addition to a physical examination, how else is AA diagnosed by your dermatologist?

6. What are some of the potential psychological challenges of living with AA?
(Circle your answer)

- a. Forgetfulness
- b. Anxiety, depression, social withdrawal²¹
- c. Eating disorders

Say it in your own words...Why is it important to share information with your HCP about how AA is affecting your daily activities and QoL?

7. In AA, inflammation disrupts which phase of the hair growth cycle? (Circle your answer)

- a. Growth phase¹²
- b. Transitional phase
- c. Rest phase

Say it in your own words...What does hair regrowth look like, and what could happen even after some hair grows back?



Preparing for Your Next Appointment With Your Healthcare Provider

Your next appointment:

Healthcare provider: _____

Date: _____

Arrival time: _____

Location (In-office or telehealth visit): _____

AAPPO Score: _____



List any other questions or concerns you would like to discuss with your healthcare provider (dermatologist, rheumatologist, primary care physician, nurse practitioner, physician assistant, or pharmacist) during your next visit:

Answer key to multiple-choice questions:

[1.a] [2.b] [3.c] [4.b] [5.c] [6.b] [7.a]

ABOVE THE SURFACE...

Scalp hair loss¹³

Eyebrow loss¹³

Eyelash loss¹³

Bodily hair loss¹³

Nail changes⁸

BELOW THE SURFACE...

Autoimmune-mediated hair follicle inflammation¹⁰

T-cell activation¹⁰

Increased inflammatory cytokines³⁴

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