

# Alopecia Areata Patient Journey



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# Alopecia Areata— the lay of the land



# About this resource

This patient journey is intended to provide an understanding of alopecia areata and the support required to help manage the impacts alopecia areata can have on daily life. It is based upon information gathered from patient and caregiver interviews, survey data and from resources provided by the Canadian Alopecia Areata Foundation (CANAAF).

This journey map aims to accurately portray the lived experiences of individuals with alopecia areata and their caregivers. It is our hope that it will serve as an important roadmap for navigating your journey, and as a guide to help healthcare professionals understand the unmet needs of their patients and the nuances of their journey.



# What is alopecia areata?



Alopecia areata is a skin condition that causes a sudden loss of hair, usually in clumps or patches.<sup>1</sup> It occurs when the immune system mistakenly recognizes healthy hair follicles as foreign invaders and begins attacking them. It is therefore regarded as an autoimmune disease. This attack causes inflammation around the hair follicles, leading to the loss of hair from the affected follicles. Hair will not grow back unless the inflammation resolves or is suppressed.<sup>2</sup>

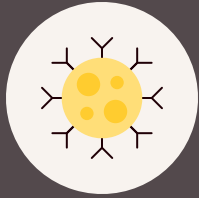


Alopecia areata is a complex condition that is driven by both genetics and environmental factors, but it is not life-threatening. It is, however, life-altering and can lead to significant psychosocial challenges for many patients.<sup>1,3,4</sup> Though there are treatment options available, unfortunately there currently is no cure, and no known preventative measures that can be taken.<sup>5</sup>

Hair loss from alopecia areata can affect any part of the body where hair follicles are present, usually beginning in a circular or oval pattern.<sup>3,6</sup> The hair loss is not always permanent, and for many it occurs in unpredictable cycles of loss and regrowth throughout their lives.<sup>1,2</sup> The nails may also be affected and can become more brittle, with tiny pits or grooves evident, especially in those who have more extensive hair loss.<sup>4,7,8</sup>

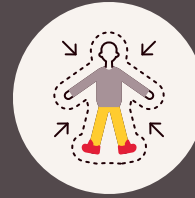
Because the hair follicles are still alive, they remain capable of regrowing hair if the autoimmune response self-resolves or is suppressed—you might regrow and maintain hair for many years, in some it may fall out again, while others will not regrow hair on their own without treatment.<sup>2</sup>





**Autoimmune disease:**

When the immune system makes a mistake and attacks the body's own tissues or organs.<sup>9</sup>



**Immune system:**

The body's defense against infections.<sup>9</sup>



**Environmental factors:**

Any external factor that influences living organisms. Examples of environmental factors are food, pollutants, sun exposure, population density, and parasites.<sup>10</sup>



**Inflammation:**

This is one of the ways the body reacts to infection, injury, or other medical conditions, and is caused by the body's immune system.<sup>9</sup> With autoimmune diseases, inflammation results when the immune system attacks the body's own tissues or organs.



**Genetics:**

The information that gets passed from parents to their children that makes you who you are.<sup>9</sup>



**Suppressed:**

When inflammation is suppressed, this means that it is controlled using medicines that seek to balance the unwanted effects of inappropriate inflammation (e.g., hair loss due to the immune system's attack on hair follicles) with the benefits of inflammation (e.g., protection from infection).<sup>11</sup>



# Who gets it?



2%

Approximately **2%** of the global population will experience some form of alopecia areata in their lifetime.<sup>12,13</sup>



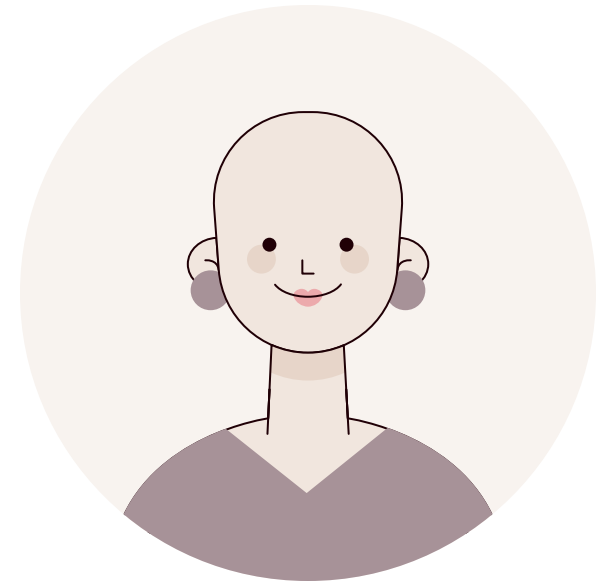
Alopecia areata can affect men, women, and children of all races, ethnic groups, and ages, but is predominantly first noticed in teenagers and adults in their **20s and 30s**.<sup>8</sup>



It is **not contagious** and does not compromise your immune system—having alopecia areata does *not* reduce the immune system's ability to protect against foreign invaders such as viruses or bacteria.<sup>14</sup>







Approximately 20% of people with alopecia areata have a family member who is also affected, indicating that there is a genetic component to the condition<sup>1</sup> Other risk factors and triggers include:

- Pre-existing immune-related conditions such as asthma, hay fever, atopic dermatitis
- Hormone changes, as seen in pregnant women or individuals with thyroid problems
- Stressful life events such as school exams, or the passing of a loved one<sup>15</sup>

However, it is important to recognize that the course of alopecia areata varies from person to person. Some have cycles of hair loss throughout their lives, while others may only ever have one episode. Recovery is unpredictable, with hair regrowing fully in some people but not others.

Every individual's experience with alopecia areata is different, and in most cases, no obvious trigger can be identified.<sup>8</sup>



# The different types of alopecia<sup>2</sup>

## **Localized alopecia areata:**

One or more patches of hair loss on the scalp. Sometimes referred to as patchy alopecia areata.

## **Alopecia barbae (BAR-bay):**

One or more patches of hair loss in the facial hair.

## **Ophiasis (oaf-EYE-uh-sis) alopecia areata:**

Loss of hair on the sides and back of the scalp.

## **Sisaipho (SIS-ay-fo) alopecia areata:**

Loss of hair on the top of the head.

## **Alopecia totalis:**

Loss of all the hair on the scalp.

## **Alopecia areata incognita:**

Diffuse hair loss on the scalp—does not form full bald spots.

## **Alopecia universalis:**

Loss of all the hair on the body including the scalp, eyebrows, eyelashes, and body hair.



# Comorbidities and other symptoms



The most common symptom associated with alopecia areata besides hair loss is changes to the nails, including pitting and the appearance of grooves. You may also experience:

- Skin sensitivity: Some have reported that this has led to hives or rashes when exposed to certain fragrances, lotions, or soaps.
- Sweating: The perspiring can seem excessive and can be a barrier to engaging in physical activities.<sup>1,16</sup>

Individuals can also have one or more comorbidities, which are conditions that someone has at the same time.



Comorbidities that can occur with alopecia areata include:

- Thyroiditis: Inflammation of the thyroid gland.
- Vitiligo: Patchy loss of skin pigmentation.
- Pernicious anemia: A decrease in the number of red blood cells due to a vitamin B12 deficiency.
- Eczema and other skin conditions such as chronic hives.
- Anxiety<sup>17</sup>
- Depression<sup>17</sup>

Alopecia areata does not cause these conditions, but they may be more likely to occur in someone with alopecia areata. There are ways to manage comorbidities and symptoms associated with alopecia areata. It is important to visit your healthcare provider regularly to discuss these management approaches—the sooner these comorbidities are diagnosed, the easier they are to control.<sup>8</sup>

*“On top of my alopecia I also had eczema, so I was dealing with rashes and redness, and my face was red, my eyes were puffy and it was really bad.”*



# How is it diagnosed?

Alopecia areata can be diagnosed with a physical exam by your healthcare provider who will look for circular patches of hair loss or other signs on the scalp with a tool called a dermatoscope. They may also look at your nails for grooves or other changes in nail structure associated with alopecia areata.<sup>18</sup> Sometimes, blood tests may be required to rule out other underlying conditions.

If it is necessary to decisively eliminate other possible causes, your healthcare provider may collect and analyze a sample of a few hairs and the skin surrounding them in a short 10 to 20 minute procedure called a scalp biopsy.<sup>19,20</sup>

The results of the biopsy are then considered with the findings from the physical exam and the patient's history to establish a diagnosis.<sup>21</sup>



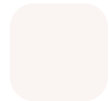
# Which healthcare providers are involved in the diagnosis and treatment?



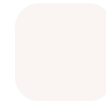
It is typically the Family Care Practitioner who will evaluate your symptoms and order the required tests to rule out other possible causes, after which a referral may be made to a dermatologist.<sup>22</sup> Dermatologists can identify useful resources and treatment options to help manage your alopecia areata, while a psychologist, psychiatrist, or social worker can be particularly helpful with management of the psychological impacts (e.g. shame, depression, anxiety), which are very common and completely normal to experience.<sup>23</sup>



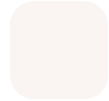
**When meeting with your dermatologist, it is helpful to arrive at your appointment prepared with questions about your alopecia areata. To ensure that you receive the support and guidance that you need, this checklist may be helpful:**



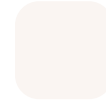
Is the dermatologist answering all your questions?



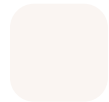
Have you been provided with sufficient education about alopecia areata?



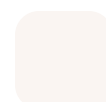
Do you feel like your time is being valued and respected by the dermatologist?



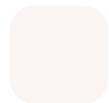
Were you given the opportunity to choose your own treatment plan from the options provided?



Is the dermatologist knowledgeable about alopecia areata treatments?



Are your mental health concerns being recognized and validated?



Are you being provided with the benefits and risks of your treatment options?



If the answer was “no” to any of these questions, tell the dermatologist about CANAAF and direct them to the resources available on our website to learn how they can better support their patients with alopecia areata.

You are in control of your medical treatment—if you would like to see a different dermatologist, speak with your healthcare provider. You may also choose to speak with members of the CANAAF community about recommendations for dermatologists in your area.



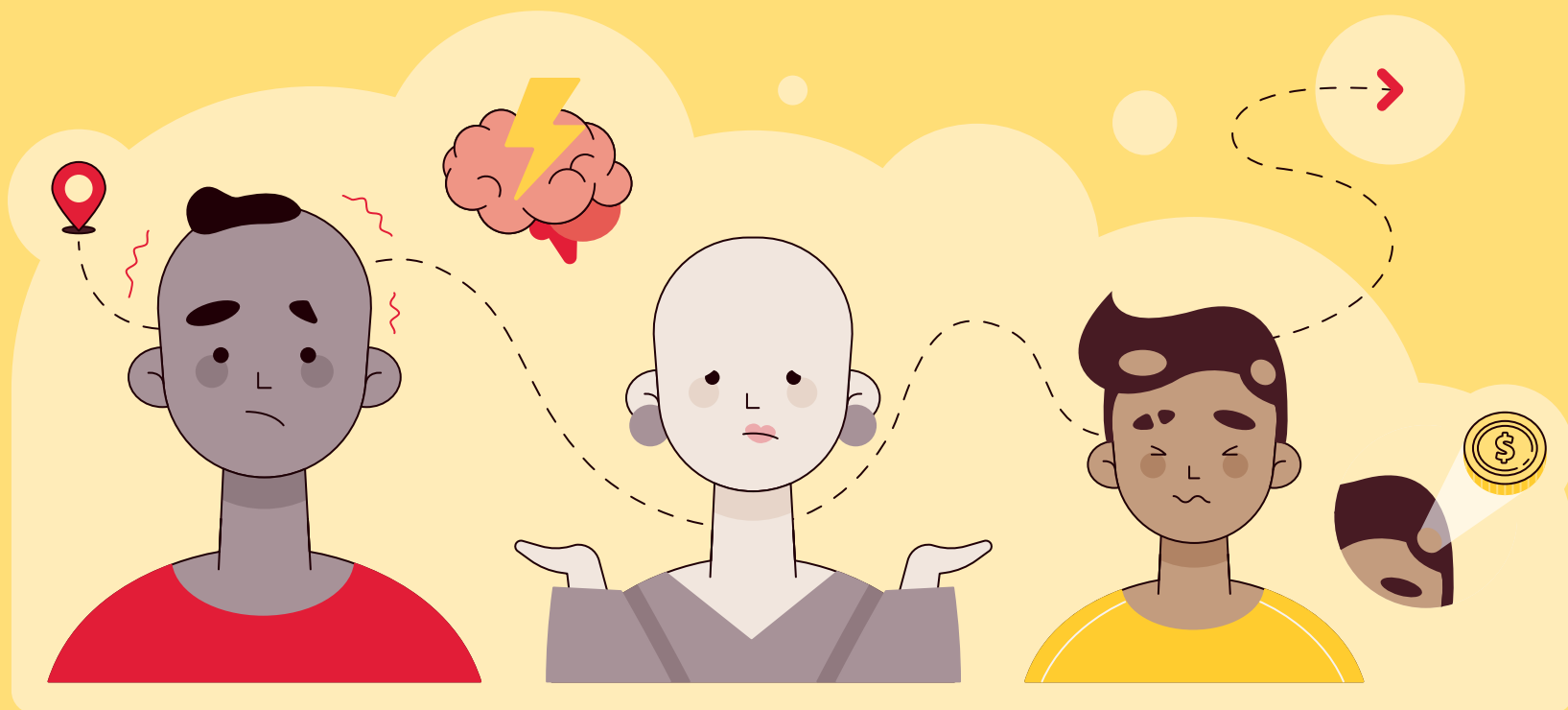
Reach out to CANAAF  
([www.CANAAF.org](http://www.CANAAF.org))  
to learn more and find  
support in your area.

Dermatologist:  
A physician  
(medical doctor)  
specializing in  
the diagnosis and  
treatment of diseases  
affecting the skin,  
hair, and nails.<sup>22</sup>

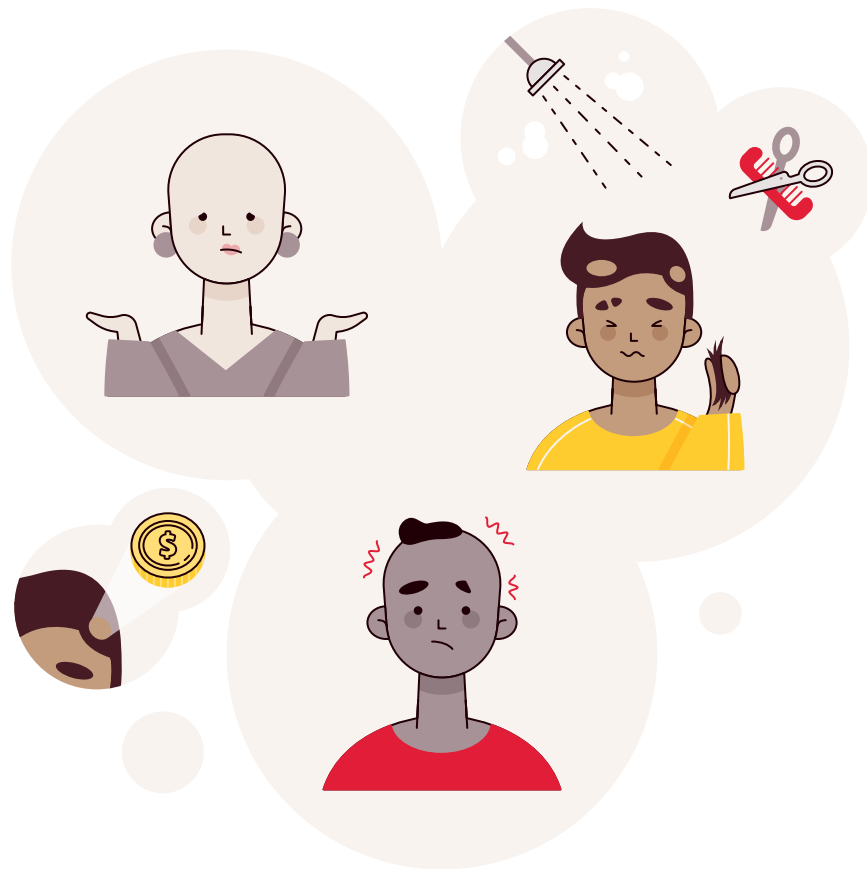




# The beginning of your journey



# How alopecia areata starts



Often it is a small, coin-sized bald patch noticed during a haircut or while showering or brushing your hair that can mark the beginning of your journey. Initial symptoms of alopecia areata, if present, can include tingling or burning sensations on the scalp followed by clumps of hair falling out in a circular pattern. In some cases, the affected areas may grow to include the eyebrows and eyelashes, or other parts of the body.<sup>24</sup>



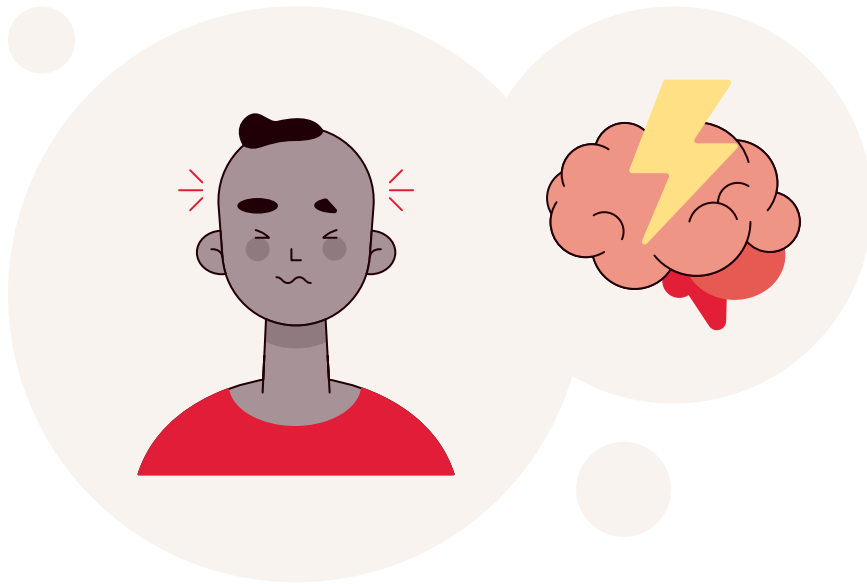
The start of this journey can be scary and confusing, often having a profound impact on your psychological wellbeing.<sup>25</sup> There is a great deal of information about alopecia areata on the internet, but it is important to know that not all of the information available will apply to you.

Speak with your healthcare provider and reach out to CANAAF ([www.CANAAF.org](http://www.CANAAF.org)) to get the answers and information that are pertinent to your circumstance, because the journey is different for everyone.

*“I was the only one at my elementary school of more than 600 students with alopecia universalis, so it was kind of scary, but thankfully I received a lot of support from my classmates.”*



# Triggers of hair loss



A common trigger of alopecia areata can be physical or emotional stress. The stress that triggers a cycle of hair loss tends to lead to further stress, triggering the immune cells to attack more hair follicles and causing more hair to fall out.<sup>26</sup>

Stress is a feeling of emotional or physical tension. It can come from any event or thought that makes you feel frustrated, angry, or nervous.<sup>27</sup>



*“My first year of college was particularly stressful. I was going to bed late, waking up early, and it was during this time that I noticed a bald patch which caused me even more stress and I found myself stuck in this negative feedback loop contributing to further hair loss.”*

People with immune or allergy related disorders such as hay fever, asthma or eczema have reported that around the time of an allergic reaction or flareup of their disorder, a cycle of alopecia areata hair loss followed.<sup>15</sup> Unfortunately, triggers of alopecia areata are not well understood.



# What to expect after a diagnosis

*“It kind of stopped my life when it first happened. It felt like my life was crumbling in front of me.”*

Because hair can be so closely linked to one’s personal identity, a diagnosis of alopecia areata can often lead to feelings of fear, shame, depression, anxiety, and social isolation, among others.<sup>24</sup> These feelings may even intensify while awaiting your appointment with the dermatologist.

People may stare, point, and ask questions, especially children, but it can be helpful to realize these reactions are coming from a place of curiosity.



*“I fear my daughter will be discriminated against, that she won’t have the quality of life that I want her to have.”*

*“We learned our daughter had experienced some bullying at her school. Since then, she’s begun wearing her wig more often.”*

*“When my daughter attended the CANAAF Annual Conference, her reaction was ‘Wow, other people like me do exist!’ The morale of my daughter increases so much every time we go.”*

If you are experiencing these feelings, it is important to speak with your healthcare provider about them as soon as possible so that you can be directed towards resources to help manage your psychological wellbeing.

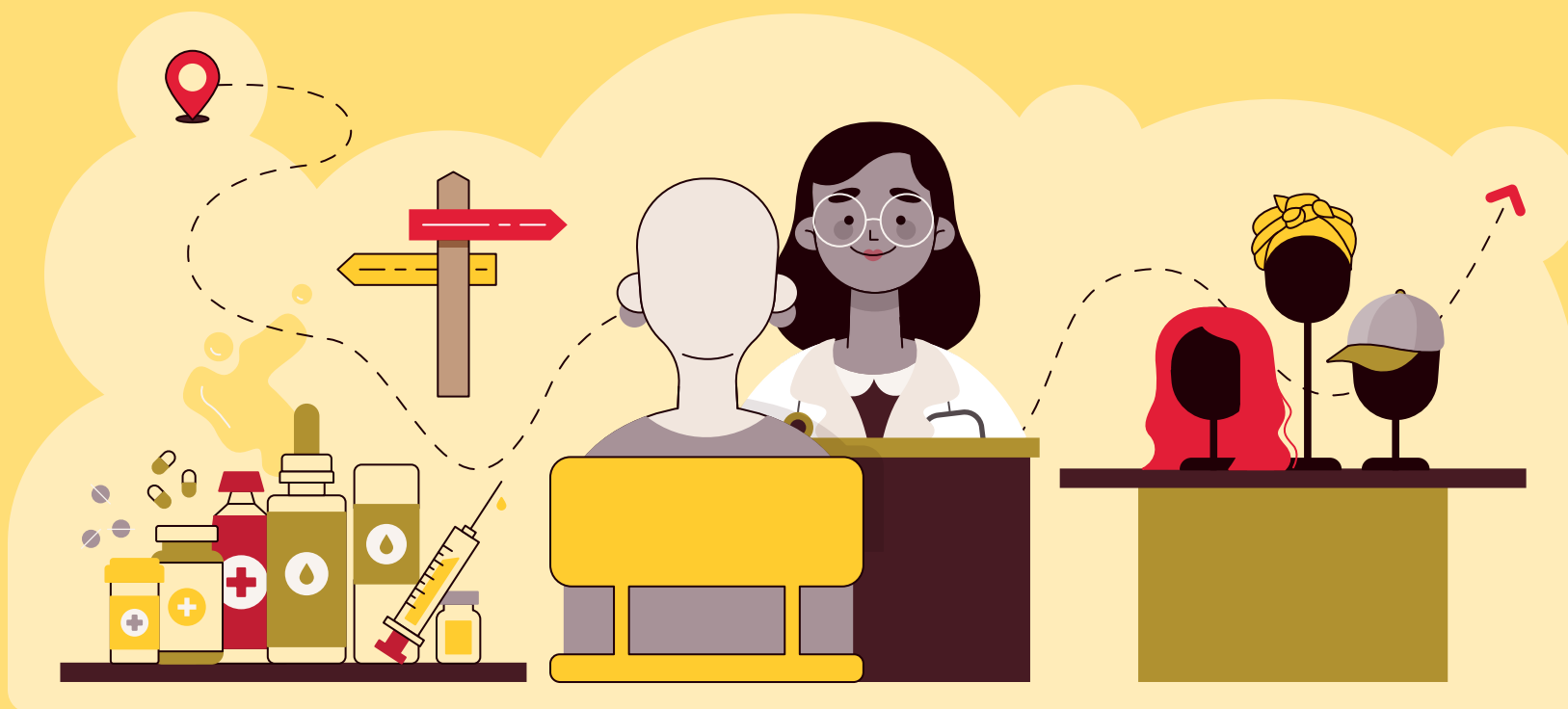
**For more urgent care, contact Crisis Services Canada at 1-833-456-4566.**

For additional information and assistance, CANAAF organizes support groups and provides peer mentorship for those living with alopecia areata, and serves as a trusted resource for guidance and information on the condition. Please visit the website to learn more at [www.CANAAF.org](http://www.CANAAF.org).

A diagnosis can also be stressful for families and caregivers who may experience feelings of fear, guilt, powerlessness, and uncertainty. In particular, parents of young children may struggle with feelings of inadequacy and helplessness in being unable to stop their child’s hair from falling out and will need support to help manage these feelings.



# Managing your alopecia areata—the road ahead





# Medical options for managing the effects of alopecia areata



Although there is no cure for alopecia areata, there are many potentially effective treatments that your healthcare provider will be able to discuss with you.

It is not always clear whether treatments will be effective given the unpredictability of alopecia areata, or if the hair will fall out again when the treatment is stopped. The course of treatment typically begins with topical treatments (e.g., medicated lotions), escalating to oral treatments (e.g., pills) and injections if required. Talk to your dermatologist about available options, and ask how long the treatment will last, how long it will take before you can expect to see results, and about the possible side effects.<sup>28</sup>



*“I learned that I was actually pretty brave—putting needles in my head, going for blood tests every month and taking medicine everyday was challenging but now that I think about it, it was all worth it.”*

*“My son has been receiving injections in his eyebrows every three months, and some of that hair has grown back.”*

Localized alopecia areata will usually respond better to treatment than more advanced forms such as alopecia totalis or alopecia universalis. However, this does not mean that advanced alopecia areata (more than a few patches of hair loss) cannot be treated. It is important to understand that you get to decide whether you would like to pursue treatment. It is your choice.

You may consider participating in a clinical trial to access experimental treatments under investigation. It is important that you speak to your healthcare provider to learn more about clinical trials and the risks associated with taking an experimental medication.

To learn more about available treatments, visit:  
[www.CANAAF.org/treatment](http://www.CANAAF.org/treatment).<sup>19</sup>

For more information about clinical trials, visit:  
[www.CANAAF.org/clinical-trials](http://www.CANAAF.org/clinical-trials).



# Non-medical options for managing the effects of alopecia areata

Measures can be taken to minimize the discomfort associated with environmental factors:

- Sunscreens of SPF 30 or higher are important for the scalp, face, and all exposed areas.
- Eyeglasses (or sunglasses) protect the eyes from excessive sun and from dust and debris when eyebrows or eyelashes are missing.
- Lubricating eyedrops can help with irritation from dust, debris and dryness.
- An antibacterial ointment applied inside the nostrils keeps them moisturized and helps to protect against germs invading the nose when nostril hair is missing.<sup>18</sup>
- Caps, scarves, or wigs protect the scalp from the sun and keep the head warm.<sup>26</sup>



When the hair of the eyelashes and eyebrows are affected, this can take an emotional toll on you as well. Research has shown that eyebrows in particular can be important for emotional expression, communication, and facial recognition.<sup>29</sup> If you have not pursued medical treatment, or if medical treatment has not achieved the success you were hoping for, non-medical options are available that have brought significant improvements to quality of life for many:

- Wigs and hairpieces have been proven to help individuals regain confidence and to positively impact how they feel about themselves.<sup>30</sup>
- Microblading involves the depositing of pigmentation into the superficial layer of the skin in a manner that resembles individual eyebrow hairs. Though generally referred to as “permanent cosmetics”, pigmentation tends to remain for 12–18 months, at which point the procedure can be redone to restore the effect.<sup>31</sup>
- False eyelashes and eyebrows can be effective cosmetic solutions if you have lost hair from these areas.<sup>8</sup>

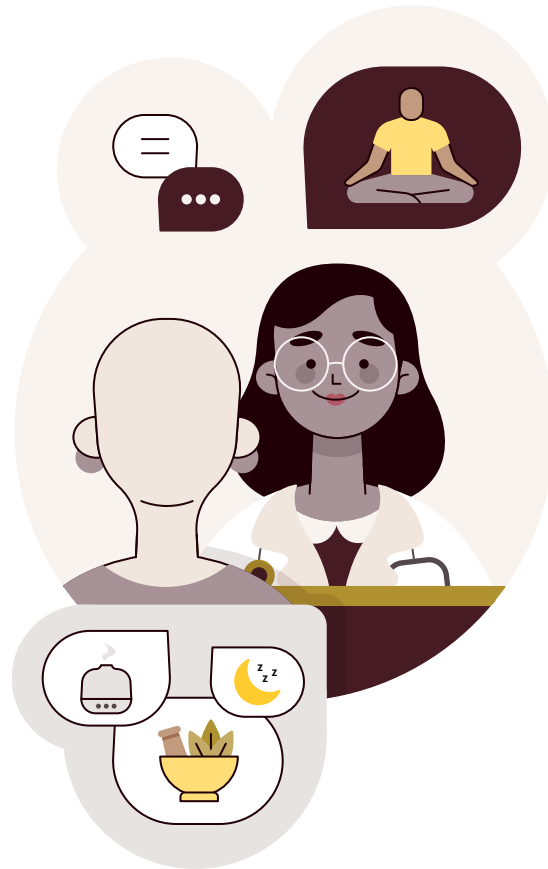
To learn more about other options please visit [www.CANAAF.org/vendors](http://www.CANAAF.org/vendors) for information about available alopecia-friendly services and products.

*“When I first tried a wig, it helped me a lot. It had gotten me to a point where I wasn’t stressed about my alopecia at all.”*

*“I don’t have eyebrows, so I have difficulty going out and making friends because I’m scared of people judging me.”*



# Alternative management approaches



It is recommended that you always speak with your healthcare provider first before pursuing new approaches to managing your alopecia areata.

In addition to the medical treatments that are available for alopecia areata, some choose to try alternative management approaches. Treatments such as aromatherapy and dietary modifications have shown some evidence of effectiveness in reducing certain symptoms associated with alopecia areata, though more research is needed. It is highly recommended that under the supervision of your healthcare provider, you consult the appropriate care practitioner such as a naturopath or registered dietitian.

Because stress can play a role in triggering hair loss cycles for some, efforts to reduce stress such as exercise, yoga, meditation, journaling, and getting enough sleep each night are not only beneficial to your health but may reduce the frequency with which you experience cycles of hair loss.



# The impact of alopecia areata — successfully navigating your journey

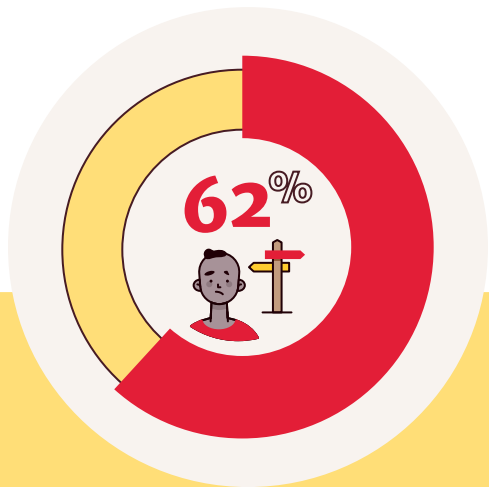


# Prioritizing your mental health

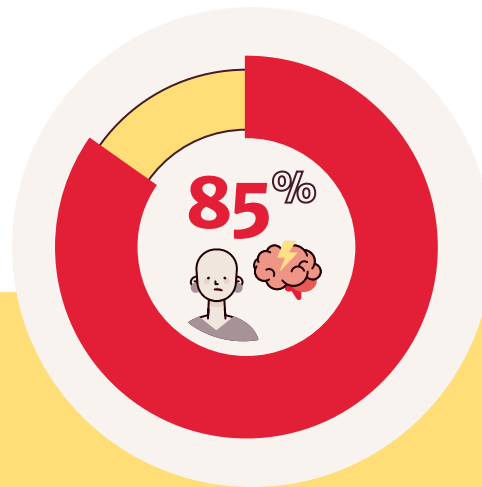
Loss of hair, at any age, can have a profound impact on self-esteem, mood, behaviour, and more generally, quality of life.<sup>32</sup> A diagnosis of alopecia areata will involve a broad range of emotional responses which vary widely from person to person. Prioritizing your mental health is instrumental to successfully navigating your journey.



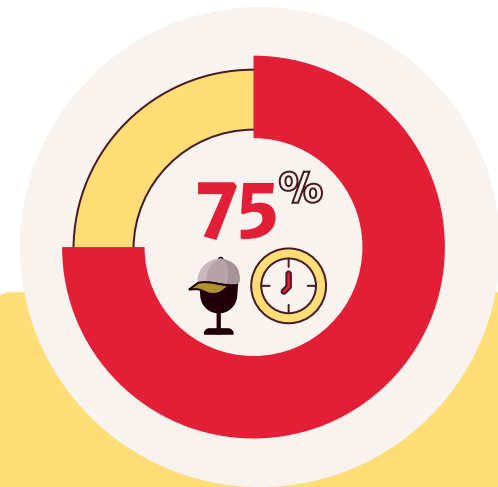
In a study published in the Journal of Investigative Dermatology in 2020<sup>33</sup>:



Nearly **62%** of study participants made different major life decisions due to their alopecia areata regarding relationships, education, or career.



**85%** reported coping with the disorder as a daily challenge, citing mental health issues, concealing hair loss, and others' reactions.



**75%** persistently concealed the hair loss, spending on average 10.3 hours per week on this.





*“My daughter thinks having alopecia is good and bad—when it’s hot, she can take her wig off and put her head underwater to cool off, unlike everybody else. But it’s difficult for her when others tease her about it—she no longer wants to participate in the sporting activities she used to enjoy.”*

*“When I was first diagnosed at 10, I thought it was kind of cool at the beginning, because I was like ‘wow, I don’t have to worry about how my hair looks. I don’t have to wash it or style it, I can just put on my bandanna and go to school.’”*

Children and adolescents with alopecia areata may experience bullying, which causes symptoms of social anxiety and depression. For teenagers and young adults, the impact of alopecia areata on self-esteem can be debilitating. Across all ages, hair loss can lead to avoidance behaviours, further exacerbating feelings of social anxiety and depression.



*“The treatments our son is receiving requires that we plan our lives around these appointments – it’s the anxiety of not making it to the appointment in time and having to delay treatment that’s the problem. If we could eliminate this anxiety, it would be good for him and for us.”*

*“In the beginning, it was really hard for me – I spent a lot of time inside my bedroom and found it very difficult to go out. I ended up losing a couple of friends as a result.”*

Alopecia areata may also adversely impact the psychological wellbeing of caregivers. Balancing work schedules with clinic appointments and familial commitments can introduce stress and anxiety leading to secondary effects upon sleep and behaviour, and an overall decrease in quality of life.

If you or your caregivers are experiencing these feelings, it is important to speak with your healthcare provider as soon as possible so that you can be directed toward the resources to help manage your psychological wellbeing.

**For more urgent care, contact Crisis Services Canada at 1-833-456-4566.**



*“Finding a psychiatrist really helped, I was really struggling. Therapy helped with my psychological wellbeing. It changed my life.”*

*“I learned that there are other people out there like me and that life will still be the same and it’s not worth all the worry, something I would have liked to have known when I started losing hair.”*

*“We sought out a psychologist for our son who was 7 at the time, and it was through the therapy that we learned he was being intimidated at school, so we have continued with the therapy every month because we’ve found it to be helpful.”*

Feelings of inclusion and acceptance are important to mental health. Alopecia areata tends to negatively affect these feelings, leading to social isolation. CANAAF offers a range of opportunities for you to engage with a community where others like you share sentiments of inclusion and acceptance.

To find out how CANAAF can help you on your journey, visit: [www.CANAAF.org](http://www.CANAAF.org).



# Advocating for yourself



Depending upon the extent and visibility of your hair loss, you may face many questions about your alopecia areata. If you identify as female, you may be mistaken for a boy, especially if your scalp and eyebrows have been affected. Some may think you are immunocompromised, assuming that the hair loss is a result of chemotherapy. Others may simply be overly curious, with their inquiries leaving you feeling embarrassed, offended, and exhausted.

*“If it’s respectful curiosity, I’ll explain alopecia to them, but it’s very exhausting to constantly have to do this. If it’s not respectful curiosity, I remove myself from the situation.”*



**You may find it helpful to advocate for yourself by anticipating these awkward interactions and preparing a brief, easy to understand description of your alopecia areata by referencing some key facts:**

## For children

- “My hair loss is not caused by cancer medicine. I do not have cancer.”
- “You can’t get alopecia areata from me.”
- “My hair loss isn’t anyone’s fault. When the body fights germs, sometimes it can get confused and think that the hair is like germs, and it will start fighting the hair which makes it fall out.”
- “Hair loss happens mostly in older people, but alopecia areata causes hair loss to anyone at any age.”
- “There are some medicines that can help, but they don’t always work.”

## For adolescents and adults

- “I do not have cancer—my hair loss is due to alopecia areata”
- “Alopecia areata is not contagious.”
- “Alopecia areata is an autoimmune disease, meaning the immune system recognizes healthy hair follicles as foreign invaders and begins attacking them, leading to hair loss.”
- “I am not immunocompromised and therefore I am not at any greater risk of infection relative to other healthy individuals.”



Involving your classmates, guidance counsellors, schoolteachers and principal in your journey early on can be an important step towards helping you feel safe and accepted at school and can help reduce bullying.

CANAAF's Classroom Package is a set of resources which can help introduce alopecia areata into the classroom environment and is available at [www.CANAAF.org/resources-for-children](http://www.CANAAF.org/resources-for-children).

Helping others to understand alopecia areata better takes a tremendous amount of courage but can lead to very positive outcomes.

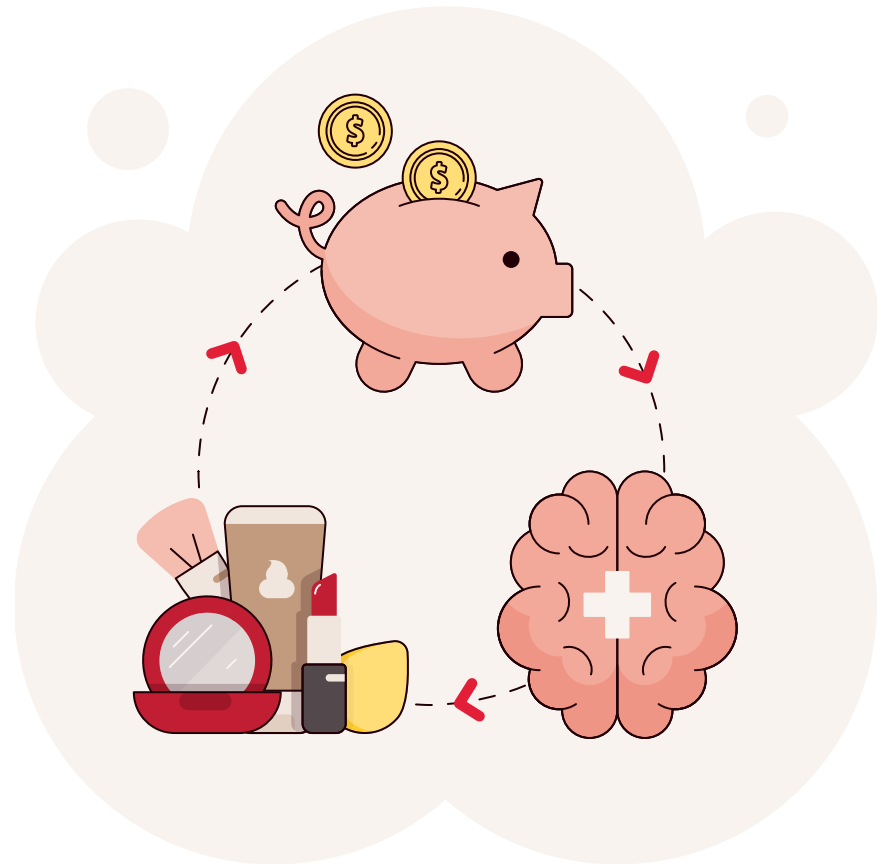
*“For my son who was 7 and had experienced some bullying, the dermatologist recommended he give a presentation to his class about his alopecia, and it was a great idea! His teachers supported him and he was able to deliver the presentation to his classmates and since then, he’s been doing great at school.”*



# Financial implications of alopecia areata

While therapy, cosmetic solutions, and topical treatments can help improve your self-esteem and overall quality of life, these options can be expensive.

*“The cost of therapy can add up. Some insurance companies cover it, but not all, and not all of the total costs. Mental health therapy can be effective, but you also have to continue going for it to help, so the cost of this therapy can also become quite expensive.”*



Taking time away from work can also become quite costly. It is important to prepare for financial burdens by investigating opportunities to receive compensation for products and services. For example, if you are employed, or if you are the dependent of someone who is employed, the employer may offer a group benefits insurance program that may help cover some of the costs of treatment.

*“The ‘Wigs for Kids’ program had been a life-saver for my daughter, but she’s aged out of the program now and we’ve learned that wigs can cost thousands of dollars.”*

*“It is critical I look put together and professional for my job, which means money spent on efforts to hide my alopecia with wigs, fake lashes and brows, alternative as well as prescription treatments—these all cost money, most of it out-of-pocket.”<sup>16</sup>*

Speak to your employer or contact CANAAF ([www.CANAAF.org](http://www.CANAAF.org)) to determine what financial supports might be available to you.

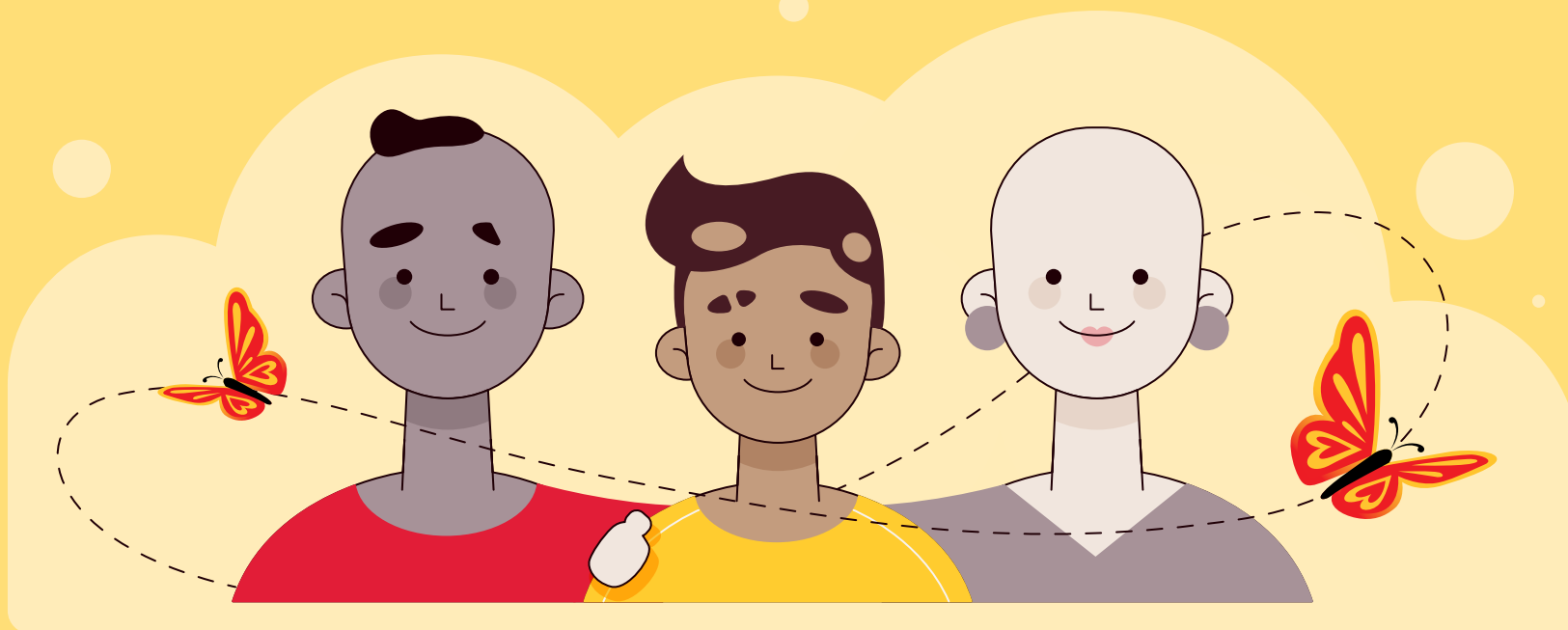
Wigs for Kids is a non-profit organization that provides complimentary hairpieces to children who would otherwise not be able to afford them. For more information, visit [www.wigsforkids.ca](http://www.wigsforkids.ca).<sup>34</sup>

The CANAAF Heads Up Fund is a financial assistance program for individuals with alopecia areata to help towards the purchase of a hair piece. For more information, visit [www.CANAAF.org/heads-up](http://www.CANAAF.org/heads-up).<sup>35</sup>





CANAAF is here to  
help you live your best life  
along your journey



There are questions you may have that cannot be answered by this journey map. If they are health related, it is important that you speak with your healthcare provider about them. For everything else, CANAAF is here to help.

The CANAAF community of volunteers and contributors have been exploring this journey together since its founding in 2008, offering the support, resources and direction needed to help you successfully navigate your journey.



To learn more about our community, engage with others like you, and learn how to confidently navigate your own journey, visit our website [www.CANAAF.org](http://www.CANAAF.org) or contact us at [info@CANAAF.org](mailto:info@CANAAF.org).

*“Because I interact with other people who have alopecia, I learn from them, they learn from me. I don’t feel alone anymore. I know if I’m ever having a really bad day, I can turn to the community, it’ll have someone that can give me some words of encouragement.”*



# Endnotes

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## About the Canadian Alopecia Areata Foundation

The Canadian Alopecia Areata Foundation (CANAAF) supports those affected by alopecia areata, promotes awareness and education of this autoimmune disease, and raises funds for research. Our mission is to offer a supportive community where we connect, learn, and celebrate together to journey through our alopecia with confidence.

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