BALD GIRLS DO LUNCH

Everyday Alopecia Guide

BGDL Resource Guide

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The Basics

Got alopecia? The *Everyday Alopecia Guide* is two books in one. It's a beginner's guide and a refresher course for living well with alopecia. It's packed with tips you can use right away.

Are you looking for new ways to think about yourself or new approaches for talking to others? The ideas here are the successful techniques I've used myself.

Most of all, I want to reassure every woman and girl with alopecia areata — whatever you're feeling — you're not alone!

About this E-Guide

Talking about alopecia areata is not easy for everyone.

I have pulled together a few of the most common questions those with and without hair loss have asked me. I have also included one of my favorite stories about a group of friends.

How Common is Alopecia Areata?

Close to two percent of the population may develop alopecia areata in their lifetimes. A small minority progress to complete hair loss on scalp, body, eyebrows and eyelashes. Most researchers consider it to be an autoimmune disorder.

Alopecia areata follows no single pattern. At one end of the spectrum, your hair may fall out only to regrow time and again. Or, you may lose it all in a few weeks. Perhaps you're a person with bald patches in random locations at random times. You could even be someone who has no hair anywhere on her body, yet persists in growing hair in one armpit.

Alopecia Areata is quite unpredictable!

We can say the same for treatments. Some topical and systemic medications work for some patients some of the time. The challenge for researchers is to find treatments which regrow hair and also keep the hair from falling out when the medication stops. Patients need treatments that are effective and safe for the long-term.

There is no cure for alopecia areata. That is why Bald Girls Do Lunch works hard to improve the quality of life for women living with alopecia today.

Take It One Day at a Time

When you have alopecia areata, your self-image may go through many changes. Fluctuations in how you feel and how you cope are common. Self-acceptance of ***your*** new normal takes time.

- **Go easy on yourself if your spirit dips from time to time.**
- **Remember, you didn't do anything wrong to cause this condition. Hair is a symbol of beauty in our culture, but your loss of hair is nothing to be ashamed of. You are still you!**

How to Handle Three Common Situations

#1: How Do I Explain Alopecia Areata to Loved Ones?

With such a small segment of the population encountering someone they know with alopecia areata, how best to explain your condition? How do you get ahead of any questions people may have? Family and friends might notice your changed appearance, yet hesitate to bring up the topic. They are looking to take their cue from you. If you don't say anything, this can get awkward as time marches on.

Here's my answer:

"Alopecia areata is not contagious, and pretty much anyone could develop this autoimmune disease. It is genetic, but not everyone gets it. It can show up at any time of life, affect people of all ages and genders, and even come and go throughout a lifetime.

Only 10% of people diagnosed have total loss of all body hair. Only one in five people with alopecia areata have a blood relative with it. There are no tests to predict who will develop symptoms or what type of symptoms.

Even though there is no cure, the good news is that someone like you or me should still live a long and happy life. There are plenty of professional and even Olympic athletes with the disease evidenced only by their bald spots or complete hair loss."

What this answer lets them know and why it works.

- It's not contagious.
- There's nothing they can do to get it, or not to get it.
- If they are a family member or significant other they will want to know what the chances are their kids will have it.
- That you are healthy, just not growing hair normally.

When the people closest to you don't know for sure what's up with your hair, their wonder could turn to deep concern. The sooner you talk about it, the better for everyone — especially yourself. The more you learn about this condition and the more opportunities you take to get comfortable chatting about it, the easier it is to be comfortable with yourself.

#2 Dealing with Surprises

You may find yourself on the receiving end of unsolicited advice. Strangers may react verbally if your scalp, hair or fashion choice reveal significant hair loss — and not in ways you like or approve of.

In today's world there is so much awareness of cancer treatments. The default assumption and common misunderstanding is that every woman (or girl) with extensive hair loss is undergoing chemotherapy. If you find that even strangers are jumping to this conclusion, you're not alone!

It may be disturbing if people stare at you. It helps to keep in mind that humans are hardwired to notice what's different in our environment. As rude as it is in our western culture to stare, most people who stare are simply curious.

At the same time, don't be surprised if you also receive surprise compliments!

Just about every woman who enjoys sporting her bald look will encounter situations like these below. People you don't know can be both well meaning and misinformed.

- **A stranger approaching with open arms, a touch on the elbow or the whisper "How are you doing?"**
- **The person behind you in line chatting up their favorite cancer support group assuming you're both in the same 'club'.**
- **A child who has yet to learn "good manners" heard yelling in the supermarket, "That lady has no hair!"**

Here's my approach:

- Use words and body language to signal that you've got a quick and confident answer.
- Be cheerful but firm. "Oh, I'm not sick. My hair just doesn't grow. It used to, but it doesn't anymore. It's not a health problem."
- Determine right away if you want to invest time to chat and educate this person or not. You're under no obligation. A spontaneous teaching moment can help you feel empowered. Spreading awareness of alopecia areata is a good thing. Yet, some days you might want to do it and other days you don't have the time or interest. It's always your choice.

- Often, if you want to wear your alopecia educator's hat, one more moment is all you need. "I've got alopecia areata. Perhaps you've seen someone else like me . . . even on television, but you didn't know it had a name." Most often, that's all it takes to calm the curiosity. In my experience, about half the time the other person might recall when they knew a classmate or co-worker with bald patches. You can suggest our website at BaldGirlsDoLunch.org as a way to learn more.

Why this works and what this tells them:

- I have met women who felt guilty after engaging in a 5-minute cancer conversation with a stranger. At no time did they ever get around to clarifying, "I have alopecia areata." As much as you feel for the person who has cancer on their radar for a personal reason, end it as swiftly as you can.
- Being quick and to the point teaches an important lesson. Even those with sickness do not want or need the help of strangers.
- Teaching about alopecia is a benefit for you and for others whom they may encounter.

#3 What to do About Advice

Plenty of people will have ideas that are rarely based in fact about treatment for your alopecia. They may be as benign as suggesting you douse your head with onion juice. Advice might come from a relative asking if you have seen the most famous specialist yet. Others will admonish you to de-stress.

What these approaches also fail to recognize is that you are suffering a loss. You may feel like you are grieving. You've lost a part of yourself.

Asking "Can't you just be happy that it's only your hair?" means they are trying to be supportive, but rarely does this reflect how you feel.

Here's my answer:

"I appreciate your concerns, but when it comes to treatments, I prefer to work it out on my own or with my doctor. Anytime I can help you learn more, there are plenty of resources and I'm happy to share them."

What this answer lets them know and why it works.

- You want their support but medical advice is not the best option.
- You leave the door open to suggest other ways they can be of help.
- It draws a line in the sand. There is nothing more frustrating than a non-medical professional giving medical advice. Ending this topic swiftly will save you a lot of trouble down the road. It might even avoid middle of the night text messages suggesting random ideas such as you change your diet.

How Two Sisters Rally for Their Friend

Ultimately it is your decision as to whether or not you tell your friends about your diagnosis. For Adrienne, a woman who lived in a small town and struggled with alopecia since she was a child, telling her friends had a profound impact on a wedding day.

Adrienne was set to be a bridesmaid for her friend, Marissa. Her friends wanted to make sure she felt beautiful, too, on that special day. Marissa and her sister Marita decided that Adrienne deserved a custom wig made with real hair. They cut off some of their own long hair so the three of them would feel even more connected on Marissa's special day.

Next, they set up a campaign using a crowd-funding website and were able to generate the $1600 they needed for the wig within days. Many of their donors were acquaintances and unfamiliar with Adrienne's diagnosis before the campaign. It resulted in a new wig for Adrienne besides more community awareness about alopecia.

How to Let Your Friends Help You

Many of the situations you may encounter involve people doing what they think is best in their desire to be supportive. What happened with Adrienne shows how wonderful creative support can be from a larger community.

Your friends and family want to be there for you. If you are open to sharing with them, you should. Let them know that the reason you told them is that you value their love and friendship. For the most part, having them there to listen to you is enough. Having someone come along to your doctor appointment provides you with extra eyes and ears. When feeling worried or anxious, some extra support ensures you don't miss anything important.

You can also let them know about certain gifts you may find helpful. What about the gift of time to join you at a wig consultation? Shop together for specialized makeup or order a comfy sleep hat from Bald Girls Do Lunch.

Your friends want to help and will welcome your suggestions.

More Ways to Support Women Like You

If they wish to donate to our cause in your honor, we are always grateful for contributions of any size. The funds we raise enable workshops, mentoring and guides like this one. We distribute Alopecia Care Kits through physician referrals. Donations help us organize private events for women with alopecia including professional makeup artists and wig stylists.

Give Today. Make women with alopecia stronger.

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