



## WHAT ARE THE HARDEST THINGS TO COME TO TERMS WITH?

- feeling unattractive
- loss of confidence
- questioning sense of self worth
- changes in body image
- acceptance of self
- dealing with the reactions of other people
- being mistaken for someone who is 'sick' or has cancer
- the unpredictable nature of the disease
- wondering 'why me?'
- not being able to do anything about it

## ADVICE FOR OTHER WOMEN

Accept that it is an emotional trauma and allow yourself to grieve. Lean on those close to you working towards a sense of self-acceptance to feel stronger. A formal or informal support group can help with this. But importantly, keep things in perspective - it's only hair and you are still you.

*"Losing your hair is hard, on you and your family. It can be physically and emotionally distressing. Look into yourself and find that inner strength. Hair or no hair - just live your life and make the best of it."*

This brochure aims to help women understand, accept and come to terms with some of the difficulties and changes that result from a diagnosis of Alopecia Areata. The information presented is the result of a survey in 2012 to which 31 women responded. 10% had some form of Alopecia Areata for less than 1 year, 25% for 1-3 years and 65% have had Alopecia for more than 3 years.

For discussion groups, social networks links and support group contact details in your area, please visit our website [www.aaaf.org.au](http://www.aaaf.org.au).

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## WOMEN

share their experiences  
of living with  
**Alopecia Areata**

# How do you tell the people around you that you have Alopecia Areata?

*Alopecia Areata is often first noticed by someone else - your family, partner or hairdresser. When and how do you tell other people? And what reactions do you get?*

## FAMILY

When telling family, many women choose to be open and honest. Some are very direct: "My hair is falling out because I have an auto-immune disease called Alopecia," while others are more concerned: "I just had to tell them what it was called and assure them that I had no (other) health concerns."

Women are concerned about the emotional impact their condition has on family: "Showing them for the first time was really hard. I hated that it made them so upset." Some people find humour can help: "Most of the time I make a joke to make them feel better about it."

## COLLEAGUES

As with telling family, the same open and honest approach is often employed in the workplace. What differs here is timing. Some people are comfortable to be upfront immediately, others will answer only if and when asked. In some cases, women may choose not to tell anyone. It really depends on the workplace. There can be difficulties when people have preconceived ideas and want to offer advice on treatment. Most reactions are described as supportive, non-judgemental and understanding.

## FRIENDS

*"I wait until I know if the friend is someone with whom I want to share personal things. Some friends do not need to be told. Others I tell when I am ready, which is generally when we are relaxed over a drink or dinner."*

Many women suggest choosing carefully which friends you wish to share this personal information with. Most reactions are positive and friends are a great source of strength. Some women report they have lost friends initially, but from that have gained a closer network of trusted people.

## PARTNER

Telling a current or potential romantic partner can be difficult, but many women agree that putting it off will only make it harder. "If they didn't hear it from me they are bound to hear it from someone else and the longer you put it off, the more uncomfortable you'll feel that you're living a lie."

Some women worry whether their partner will still love them: "He is tolerant with me but I don't know how long he will tolerate my appearance and my sadness due to Alopecia." Others take an approach of 'he loves me, not my hair' and find it makes little difference to their relationship: "The more confident I became about my situation, the less he cared and he now encourages me to wear a bandana or go bald on holidays. He is very supportive."

## WHAT HELPS YOU TO COPE?

**RELAX, SMILE, TALKING, FRIENDS, LAUGHING, GRIEVING, OTHER PEOPLE WITH ALOPECIA AREATA, HUMOUR, SUPPORTIVE FAMILY, CRY, WIGS & HATS, ACCEPTANCE OF WHAT IT IS, PROFESSIONAL CARE, CHOCOLATE, DON'T LET IT CONSUME YOU, DO THINGS THAT MAKE YOU HAPPY.**



*"I don't automatically tell everyone. It is my business. Generally, after a work relationship has developed, I might tell a colleague or two. It usually goes without issue, because adults at work really do have other things going on in their lives and they never seem that interested when I nervously tell them that I don't have hair."*

*"I understand life's challenges living with Alopecia. I am a dancer, a dance teacher, I work in administration and recently became a mother. Life moves forward and having Alopecia Areata should not restrict a lady from achieving her goals." Shea.*