

The mental despair of alopecia

SCENARIO

A patient gives her perspective on a difficult condition.

Mrs Patricia Fogarty

MARTIN Luther in the 15th century is quoted as saying: "The hair is the richest ornament of women." Many of the young men who have alopecia would agree that this quote also relates to them.

Alopecia is an autoimmune disease that can strike anyone at any age, from the very young to older adults. The diagnosis can be devastating, and sometimes little or no treatment is offered.

Growing up with alopecia has indeed been challenging. I was first diagnosed at age seven, when patches developed around the crown of my head, and my hair thinned out all over. The first treatment offered by my dermatologist was ultra violet ray treatment, and this worked for a while.

The patches would return at regular intervals and then my eyebrows and eyelashes would disappear. I was constantly told that my hair loss was exacerbated by stress, and if I could stop worrying about it, my hair would grow back. This created a cycle of despair, because watching your hair fall out was indeed very stressful,

and thinking you had contributed to it just made everything worse.

I was injected with cortisone on my eyebrow line to help regrowth, and again this worked for a short time. Minoxidil was used as a cream to rub onto the patches, as well as an abrasive concoction to stimulate the hair follicles. I was prepared to try anything to make my hair grow, but in the end the constant failure of these treatments was soul destroying.

At age 26, following the birth of my daughter, all my hair fell out – alopecia universalis – and I had to face the fact

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that it would not grow again. At that time there were no support groups, little was known about what caused hair loss, and I was told to stop seeking treatment and get on with my life.

The next step was to purchase a wig to maintain a "normal" appearance. A simple wig purchased at a department store was hot, uncomfortable and easily displaced. Luckily, this was at the time suction-based human hair wigs were being developed. This of course came at a price, approximately \$3000 for a wig that lasted for 2-3 years. To this day little or no funding is available to people with alopecia,

and a wig attracts GST, whereas all other medical prostheses are GST free.

I have noticed over the years of total hair loss that my body temperature is affected. Lack of body hair means I feel the cold and the heat more than the average person. This is something rarely mentioned when talking about alopecia.

Loss of hair can mean the loss of identity to some people. Many hide the fact that they have no hair, and become introverted and extremely vulnerable. Every time you open up a magazine the emphasis is on beauty, hair and makeup. When

Britney Spears shaved off all her hair the world was horrified. Most people strive to look 'normal' and not stand out. This is just human nature. It is also true that:

- Many with alopecia are wrongly thought to have cancer.
- Many suffer from bullying at school.
- Many feel isolated and embarrassed.
- Many just want it to all go away.

This is why doctors should follow through with their patients and make sure their mental health status is stable, and that it is maintained.


Counselling and continual encouragement are essential. A mental health care

plan may be extremely beneficial.

Nowadays there are support groups. The Internet has opened up the world, and it is helpful to direct people to a support group from which they can find comfort and hope.

A group called the Princess Charlotte Alopecia Foundation (www.princesscharlottealopecia.com), based in Sydney, aims to provide emotional support to those with alopecia and their families, educate the public and create awareness of alopecia in Australia and New Zealand, and to provide financial assistance to those who struggle with the cost of a wig.

It also aims to gain the support of our Federal Government in providing more adequate financial support in the purchase of wigs.

When you next see a patient who has alopecia please remember that they may not be coping. Just spend a little time to see that all is well. 

Mrs Fogarty has donated her payment to the Princess Charlotte Alopecia Foundation.

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Do you have a memorable real case? Write it down in 700 words and email it to margaret.hamilton@medobs.com.au or fax 02 9902 7778.

