

# Helping Children Cope With Hair Loss

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*Alopecia totalis and alopecia universalis are emotionally devastating forms of hair loss, which are difficult to cure. When childhood hair loss is unresponsive to alopecia therapies, both traditional and nontraditional, children may be stigmatized and fall under extreme psychologic distress. The not-for-profit organization Locks of Love began providing custom hair prostheses to children in 1997 and has continued to serve the emotional and cosmetic needs of children with extensive hair loss.*

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During the formative childhood years, it is difficult for children to feel different from the crowd. In the preschool years, children approach unique appearances with questions such as “Why do you look different?” or “What is that brown spot on your face?” School-aged children generally are more derisive than inquisitive, and children with unusual physical characteristics often become targets of teasing. Many school-aged children lose their hair to medical causes such as the autoimmune disease alopecia areata or cancer chemotherapy.

In patients with alopecia areata, the hair follicle stops producing hairs because of an autoimmune attack against the inner root sheath, matrix, dermal papilla, and hair shaft,<sup>1</sup> which leads to cell-mediated immune injury of the hair follicle and subsequent hair loss.<sup>2</sup> Although most cases of alopecia are localized and self-limited, there are a number of more severe variants: ophiasis alopecia areata, which involves

the hairline; diffuse patchy alopecia; alopecia totalis (complete loss of scalp hair); and alopecia universalis (loss of hair over the entire skin surface).<sup>3</sup>

A variety of therapies can be used to treat severe variants of alopecia areata, including: (1) topical immunotherapies (eg, squaric acid dibutyl ester, diphenylcyclopropenone, dinitrochlorobenzene), which cause irritation, pruritus, and occasional urticaria<sup>4</sup>; (2) oral corticosteroids, which cause growth suppression, cushingoid features, hypertension, and glucose intolerance<sup>5,6</sup>; and (3) psoralen plus UVA, which involves long-term compliance with 30- to 40-minute twice-weekly therapy sessions and causes phototoxic scalp reactions (making it difficult for children to comply).<sup>7</sup> Although medical therapies are very helpful for regaining hair lost because of alopecia areata, there is a subset of alopecia areata patients who cannot regain hair with these therapies or who are not willing to accept the side effects of current therapies.

Hair loss can be especially devastating for girls, for whom baldness at any age is cosmetically unacceptable. Alopecia areata causes psychosocial morbidity and has a negative impact on the quality of life of affected individuals.<sup>8,9</sup> Even when therapy is successful, it may take as long as a year before an acceptable length of hair can be grown for a girl. Patients undergoing chemotherapy may require years of therapy, during which hair growth is aborted by antimetabolic agents. One of the top 5 factors that negatively affects the quality of life of patients treated with chemotherapy is the alopecia caused by chemotherapeutic agents.<sup>10</sup> There are many medical conditions associated with long-term medical hair loss (eg, radiation therapy to the scalp, burns, lupus, dermatomyositis).

Hair is cosmetically essential for children's self-esteem and, sadly, to their social acceptance in many settings. In 1997, the not-for-profit organization Locks of Love began offering professionally fitted and beautifully crafted hairpieces and wigs to children with medical-grade long-term hair loss.<sup>11</sup> The organization, based in Lake Worth, Florida, offers hope of an acceptable physical appearance for

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**Figure 1.** Donor hair before being cut. Photograph courtesy of Locks of Love.

individuals aged 6 to 18 years who are unable to afford costly hairpieces. Children in the United States and Canada who have long-term hair loss due to medical reasons are eligible. Hair prosthetics are available to boys and girls of all ethnicities. Since its inception, Locks of Love has made more than 2000 prosthetics.<sup>11</sup>

Professionally fitted prosthetic hairpieces cost \$3000 to \$6000 and are not available everywhere.<sup>12</sup> Because of the customized fit, these prosthetics can be worn while swimming. They are lifelike and visually realistic due to the manufacturing technique. A cap with a synthetic scalp is made to match the recipient's skin tone and is fitted to the child's scalp so that the cap will lie comfortably on the head with little movement. A mold is made of the child's scalp by a parent or friend. Then, the mold is made into a specially fitted cap that is supple and slip proof. More than 100,000 hairs are handwoven in a natural single-hair pattern throughout the scalp cap, creating a natural appearance. Locks of Love offers new professional hairpieces every 18 months to children aged 6 to 18 years who have previously received one (maximum of 5 hairpieces).<sup>12</sup> Children younger than 6 years have rapid scalp growth; therefore, frequent

replacement of hairpieces or hats is necessary. For this reason, Locks of Love offers younger children less expensive wigs until the children are old enough to be fitted for the custom-made caps.

Beyond the dollar value of these wigs are the lives touched by this organization. Children with alopecia totalis or alopecia universalis, the most aggressive forms of alopecia areata, are the main recipients of Locks of Love's hairpieces.<sup>11</sup>

Many children with alopecia areata avoid socializing because of their hair loss. Recently, I had the opportunity to interview one such recipient, Nadia (a pseudonym), and her mother (August 2006). Nadia is a 12-year-old girl in fifth grade who developed alopecia totalis at the age of 16 months. Until she was 7 years old, Nadia did not have a hairpiece and was fussy about putting on hats. She attended school with no hair and recalls being stared at. "I would just look back at them and smile until they looked away," she said. In second grade, Nadia's mother received information from a local dermatologist about Locks of Love. Despite initial nervousness, the mother explained that the results of the process were "awesome." The family received a package containing an instructional video and everything needed to make a plaster mold of Nadia's head. With the help of a hairdresser, a mold of Nadia's scalp was made at home and sent to Locks of Love.

In a few months, a hair prosthesis arrived with a wig stand and wig brush. Nadia and her mother were thrilled! After receiving her first hair prosthesis in reddish-brown, Nadia reexamined the hair colors offered by Locks of Love and decided to change to strawberry blonde. I asked Nadia if blondes had more fun and she replied, "I don't know about that, but it's really awesome to be like everybody else and really fun to play with the hair." Nadia enjoys styling her hair and having her sister style her hair. Nadia's hairpiece is allowing her to enjoy her childhood without being teased or tormented. She looks forward to starting middle school wearing her third prosthesis; she said, "Most of the people in fifth grade knew I had alopecia. In my new school in sixth grade, no one will know I have alopecia." Blending into the group is a major coup for a preteen. Nadia can wear her hairpiece in class or while playing third base on her softball team.

The beautifully crafted hairpieces from Locks of Love help children regain self-esteem and restore quality of life. An adult with hair loss ultimately may choose to go without hair, but children and adolescents usually wish to fit into the mainstream physically and cannot deal with a hairless appearance.

Locks of Love is kept afloat by 3 kinds of donations—money, time, and hair. Dollar donations



**Figure 2.** Donor hair in a ponytail for easy cutting. Photograph courtesy of Locks of Love.

help go toward the cost of manufacturing wigs and operating an office. Time can be donated by setting up fundraising events, cutting donors' hair, and volunteering in the office (for those in the Lake Worth area). The third and equally loving donation is one's hair. If an individual is cutting more than 10 in of hair off, Locks of Love will accept the hair to create a hairpiece (Figures 1–3). Donated hair should be unprocessed, naturally pigmented (no bleaches or gray hair), more than 10 in long, and sent dry and bound by a rubber band (in the form of ponytails or braids) in a plastic bag.<sup>13</sup>

Above all, Locks of Love focuses on the patients. This year, the organization is aiming to increase the number of hairpieces it creates. At this point, through efficient management and hard work, Locks of Love has no waiting list and is seeking eligible recipients for their prosthetic devices.

If you would like to refer a patient or send a donation, please contact:

Locks of Love  
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Suite 102  
Lake Worth, FL 33461  
Telephone: 561-963-1677  
Web site: [www.locksoflove.org](http://www.locksoflove.org)

**Figure not  
available online**

**Figure 3.** Donor holding her donation. Photograph courtesy of Locks of Love.

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