



Information about Albinism

National Organization for Albinism and Hypopigmentation

Social and Emotional Aspects of Albinism

Society's attitudes about albinism have a tremendous influence on the person with albinism. These influences will vary from person to person and at different stages of life. Having albinism also has a tremendous emotional impact on the person which also vary from person to person and vary at different stages of life. It is in the balance and interplay between the external world and each individual's internal response that a sense of self is born and sustained. Albinism is an important part of that sense of self.

The First Influence: A Disability or Not?

Neither the general public nor those with the condition agree about whether to identify albinism as a disability. This ambiguity creates a problem in the language used to talk about albinism.

It also makes it difficult for those with albinism to identify themselves as a group. In many ways, albinism is a unique condition. That uniqueness, however, leads to separateness and isolation for many people. Social attitudes toward albinism are often similar to those experienced by other disability and minority groups. These attitudes include a lack of understanding, fear of the unknown, and prejudice based on appearance.

The Americans with Disabilities Act defines disability with respect to an individual as "a

physical or mental impairment that substantially limits one or more of the major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment." Since albinism involves a visual impairment, some people consider it a disability. One definition of handicap is "the obstacles a person encounters in the pursuit of goals in real life, no matter what their source." Thus a person with a disability may or may not be handicapped in pursuing the life they want to live.

The identification of albinism as a disability is complicated by the concept of legal blindness. In the United States, a person is legally blind if his or her vision cannot be corrected with glasses or contacts to better than 20/200 in his or her better eye. By this standard some with albinism fit the legal category of visual impairment and some do not. Yet, in spite of varying visual acuity, many of the problems experienced by those with albinism remain similar.

The Second Influence: Physical Appearance

The first aspect of albinism which most people notice is the person's unusual appearance. The white hair and skin of oculocutaneous albinism is a powerful factor from the moment of birth.

The new baby will often be much lighter in color than any family member. In non-white races the coloring of the baby with albinism is a dramatic contrast to the family and community. Color is a highly charged characteristic in our culture now and historically. Strangers will often make unwanted and unkind comments about the appearance of a child.

Beyond color, a child's eyes may be moving rapidly and not focusing together. The child may have to squint, tilt his or her head, and hold things close in order to see. Children with albinism often use glasses and optical aides to enhance their vision. Therefore the child with albinism often feels isolated not only in physical appearance but also in the conduct of everyday life.

This perception of being different can lead to an immense effort to act as much like "normal" as possible. A person with albinism can feel a lot of pressure, both from themselves and from other people, to minimize the differences albinism causes. This effort can result in a great deal of stress for a person continually trying to maximize visual ability. The pressure can even lead a person with albinism to deny entirely that he or she has albinism, thereby losing touch with a very important aspect of one's identity.

Family and close friends can counter this isolation and denial. Being prized and valued as a whole person is the foundation for a lifetime of self-esteem and inner strength. This prizing must include an honest acknowledgment and acceptance of the condition of albinism. It is vitally important that families can freely discuss the impact of albinism in each of their lives.

The Third Influence: Language, Myth, Stereotype

Language can shape ideas and create reality. The word "albino" is commonly used in many languages including English. Some people are comfortable with the word and prefer being called an albino. However, people often use the word "albino" in hurtful ways. Many feel it is dehumanizing to refer to a person in terms of a condition. Although slightly cumbersome, the terms "person with albinism" and "people with albinism" put the person first and the condition second.

Teasing and name-calling are other ways in which language can be very dehumanizing.

Almost all children face teasing during their school years and they need to develop positive coping strategies. Parents, teachers and increased education about albinism can help with this problem. (See also "Coping with Teasing and Name-Calling" on page 3 of this bulletin.)

Throughout the world, people have misconceptions about albinism, ranging from notions that people with albinism have magical powers to the belief they are retarded. These run the spectrum from the notion that those with albinism have magical powers to the belief that they are retarded. Among African-Americans, a common myth is that babies with albinism result from a union between an African-American woman and a Caucasian man. Another common myth is that people with albinism must have red eyes. People with albinism usually have blue or gray eyes which sometimes appear reddish in certain types of light. Sometimes, myths are so widespread even the person with albinism believes them.

The media, including literature and film, have contributed to stereotypes of albinism. The character with albinism is often portrayed as villainous, deviant, supernatural or sadistic. Also some news reports and encyclopedia articles have included false or incomplete information about albinism. It is difficult for the public to know what is true and untrue about albinism.

The Fourth Influence: The Family

It is vital that the family have accurate information about albinism. New parents need support and time to understand the condition of their child. Parents and family members may need to face some unpleasant stereotypes they have learned about albinism. Siblings need to understand why their brother or sister looks different and why they seem to be getting so much attention. There is no single force greater than the family in helping a child understand and accept himself or herself.

The Emotional Component of Albinism

Along with the external influences of society, every person has a vital and essential emotional response to their personal experiences with albinism. These personal responses shape who we are and how we adapt to albinism. A strong emotional response is a normal part of living, growing, and intellectual development. Suppressed emotions often turn inward and cause stress, depression and physical maladies.

Emotional responses to albinism will occur throughout life because of the many challenges and frustrations the condition presents and the many societal influences already mentioned. It is very important to develop healthy ways to express and integrate these emotions. First, it is necessary to recognize feelings and determine their source. Parents can help children label the feeling the child feels, then help the child connect that feeling to a specific reason or event. For example, a parent might say, "I know you're sad because you have to put on sunscreen before you go swimming." Then the parent can help the child "do" something with the emotion such as to talk about it, play, yell, run, cry—whatever physical outlet will release the feeling. This validation and release are essential in processing an emotion.

Adults with albinism can go through this process by having friends and family listen to their frustrating, discouraging, or proud experiences. Some ways to release an emotional charge are physical activity, taking action in the form of education or advocacy, journal and letter writing, or doing something nurturing for yourself. Sometimes professional help from a therapist or counselor can assist a person work through the highly charged issues of albinism. Coping with albinism often isn't easy. However, working through the issues albinism causes not only leads to great personal satisfaction, but also to a greater understanding of human kind.

Conclusions

A very basic human need is to be "seen" "by another person—to be known and to be accepted. This is poignantly true for the person with albinism who may be immediately "noticed" by many, but truly "seen" by few. This explains why it feels like a hidden condition despite its obviousness.

NOAH provides an opportunity for people with albinism to get together and share their experiences. Being involved with others is a way to decrease isolation and share in the combined knowledge and experience of the group. It is a way to gain confidence and strength in meeting the challenges of this condition.

Albinism, often unexpected in a family, can be a catalyst for acceptance, understanding, and love that encompasses all family members and each of their individual differences. It is a physical manifestation of uniqueness, with unique joys and hardships. Through the efforts of dedicated families and individuals albinism is becoming known and understood.

—June Waugh, MS, Licensed Marriage, Family and Child Counselor, NOAH Board of Scientific Advisors

Coping with Teasing and Name-Calling

At NOAH events and on NOAH's website, many preteens and teens with albinism share experiences and reactions to teasing. Many parents said that teasing, insensitivity, and ignorance about albinism were their greatest challenges.

The young people reported being called names like "Whitey," "Snow White," "Casper," "Four Eyes," "Blind Eyes," "Grandma," and "Grandpa." They were asked why their heads shake, did they

pour bleach all over themselves, and other embarrassing questions. They also reported being excluded from games because they weren't "good enough."

I, too experienced many of these same things. I was asked once if I could see in the dark. Another time a complete stranger walked up behind me and demanded that I look at her. I think she wanted to look at my eyes.

Understanding this behavior is one of the first steps in learning to deal with these experiences yourself or to help your child cope with albinism.

What makes children (and others) tease and engage in name-calling? What causes the crude remarks, the callous behavior and the insensitive questions?

One reason may be fear. Ancient people believed that to name something was to control it. We know today that people can be controlled by repetitious name-calling when they begin to believe the name, and act accordingly.

Other reasons for name-calling, teasing and insensitivity are lack of knowledge, curiosity, a genuine desire to learn, and an inability to express questions constructively.

Some people tease in order to get to know another person better or to express affection. This kind of teasing usually isn't hurtful. However, if the person being teased doesn't have a positive self-image, and isn't comfortable with albinism, even affectionate teasing can hurt.

First, develop a positive self image and a positive attitude towards albinism. Add to that a thorough knowledge of albinism itself and you'll find yourself becoming more comfortable when discussing it with others. The standard "dumb"

questions can become opportunities for education if one has self-confidence.

Parents can help their children deal with the hurtful comments by encouraging them to share their experiences and their feelings about them. Parents can also help their children by exploring new and positive ways to respond to the teasing and name-calling in the future and by practicing through role playing.

Sometimes presenting information in class about albinism can reduce the amount of teasing and name-calling. Parents or the student can make the presentation, depending on the circumstances. Parents may need to educate the teachers first.

Schools should teach kids that hurtful behavior towards people with any sort of difference is a form of discrimination. A series of lessons on disabilities can provide information about albinism in the context of a variety of disabilities and other differences. Videos, puppet shows such as Kids on the Block, and other materials can teach this lesson on a child's level.

Others in NOAH have additional ways of dealing with teasing and name-calling, such as using humor. At NOAH gatherings and on NOAH's Albinism Online Community at www.albinism.org, children and adults with albinism share their own ways of coping with albinism.

— *Janice Knuth, MSW, ACSW, LSW, President, NOAH 1982 – 1993*

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