

HYPOHIDROSIS:

How To Stay Cool When You Can't Sweat

Sweating

People with some types of ectodermal dysplasia — including hypohidrotic ectodermal dysplasia (HED) — cannot sweat to cool their bodies when exposed to warm or hot environments. The inability to sweat is called hypohidrosis and is caused by a decrease or total absence of sweat glands, a condition which can be determined by a skin biopsy of the scalp. This procedure may be done by a dermatologist.

Fortunately, in some cases, individuals who have HED may find that their ability to sweat improves during adolescence. However, all people with decreased or absent sweat glands can easily become overheated.

The good news is that individuals with ectodermal dysplasia are able to engage in most activities, including team athletics. It is important, however, to be aware of the possibility of overheating and if overheating occurs, to treat it immediately. Prolonged elevation of body temperature is dangerous and can be life threatening.

It is also important to remember that heat is not the sole source of difficulties. Humidity must also be taken into account. For example, an individual affected by an inability to perspire may have more difficulty on a moderately warm day with high humidity, i.e. 76 degrees with 20% humidity. Experience is often the best teacher of what can and cannot be tolerated.

Overheating

What Are The Signs Of Overheating?

It doesn't take long for a parent or caregiver to recognize when a child is overheating. Parents of children affected by ectodermal dysplasias often mention reddening of the ears as an early indicator. A head warm to the touch is another frequently mentioned sign. Irritability and lethargy may follow. More serious situations can be accompanied by



dizziness and/or nausea and may serve as a precursor to heat stroke. Heat stroke is a life-threatening emergency. If mild dizziness or nausea is present, treat aggressively with cool liquids to drink; a cool bath or ice packs placed at the armpits and groin; and resting in a shady, cool area. If confusion, disorientation, fainting or vomiting



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Young baseball players have sought the shade of a power pole in the outfield, toddlers have used popsicles for head coolers, and others have sought the coolness of a linoleum floor by laying on it. Some kids wear dampened shirts or caps, some carry squirt bottles, and others plan their activities to limit exposure on days with very warm temperatures.

There are families who choose to visit amusement parks or zoos on cloudy days—often when they are least congested, which gives an added bonus. The important tactic is to plan for safe outings using whatever precautions are deemed appropriate for the situation.

As the child grows, families may want to act as chaperones on school outings. When school buses that are not air-conditioned are used for field trips, parents may find it useful to accompany the group in a separate vehicle just in case a source of air-conditioning may be needed.

Does The Need For Cooling Change Over Time?

Families experienced with ectodermal dysplasias tell us that the greatest difficulty with the heat seems to be present in younger children, from birth to five or six years of age. Why the difficulty seems to lessen with age is anyone's guess. Some surmise that increases in body size with age and growth may play a role.

Others think that children learn to do a better job of managing their activities and thereby function better in warm environments. A number of adults affected by ectodermal dysplasias indicate that changes at puberty include a new ability to minimally perspire on the palms of the hands and soles of the feet. Most children affected by ectodermal dysplasias learn to manage their inability to perspire as they age.

Can Individuals Affected By Hypohidrosis Participate In Sports?

Yes. The NFED has ample evidence of individuals who have successfully participated in athletics including football, basketball, baseball, track, soccer, gymnastics, swimming, martial arts, bowling, etc. Included in that number are some individuals who were extraordinarily successful and deemed champions in their sport.

occur, call 911 and treat as above while awaiting emergency personnel.

Can Brain Damage Occur Because Of Overheating?

The quick answer is “yes”. This is rare, usually in individuals who have not yet been diagnosed with ectodermal dysplasia and who are not aware of the risks of high fever. If you are aware of the information regarding overheating in this article and follow the recommendations, the risk of brain damage is extremely slight. Normal body temperature is around 97-100.5 degrees F. It is important to remember that children with routine illnesses commonly have fevers reaching 104-106 degrees F with no ill effects.

Will Children Who Can Not Perspire Know Whether Or Not They Are Overheating?

This is a concern for most parents; but individuals with experience can share countless stories which indicate that children who cannot perspire feel heat just as adults do and instinctively seek relief. There are some children who may not want to acknowledge that they are hot. However, experience has shown that they catch on quickly and soon learn helpful cooling techniques. It's amazing how they will seek out shade or use resources at hand.

Allowing children to try various activities enables them to learn whether or not they like the sport; how to accommodate their inability to perspire; and when to acknowledge that some activities may require more than their bodies can comfortably deliver.

Should We Move To A Cooler Climate?

While living in Alaska might seem attractive, unless you have job portability, such a solution may be impractical. In reality, families affected by ectodermal dysplasias live in every state and probably every country on the globe. Individuals living near deserts or in the warmest of climates have successfully accommodated any cooling needs.

Should The Child's School Be Air-Conditioned?

The effects of warming on the body of individuals who cannot perspire are such that performance at school and on the job can be adversely affected. As indicated previously, irritability and lethargy are common effects, which can inhibit performance.

Schools are mandated by public law (P.L. 94-142) to provide special education and related services for those with disabilities. While that seems rather straightforward, school administrators and school boards are sometimes reluctant to provide what many consider luxury. However, the need for air-conditioning can be well documented and should be provided to assure that individuals affected by ectodermal dysplasia can function appropriately.

Begin by talking with the school principal and/or nurse to determine the procedure you must follow. Do this well in advance (at least six months) of the beginning of school, as there may be a variety of delays that can prohibit timely installation of equipment. For additional information and procedural suggestions, contact the NFED office.

Cooling Products

What Are Cool Vests?

Cool vests typically use gel packs that are frozen and then inserted into the vest. These vests are often light-weight. Most cooling vests are custom made for the wearer to assure proper fit.

Are Cool Vests Used All Of The Time?

Generally, the bulkiness of most cool vests makes them impractical for constant use during routine

day-to-day activity. They can be cumbersome for small children and may bring additional unwanted attention to ectodermal dysplasia. However, they can be quite useful in certain special situations, i.e. lengthy rides on unairconditioned buses, for highway construction workers, as a means of portable cooling for athletes, etc. Familiarity with the various products available will enable families to make the cooling decisions which are best for them.



Is A Cool Vest Appropriate For My Child?

A parent's responsibility is to provide a method of cooling which is appropriate for that particular child. If there are special circumstances where a cool vest is necessary, then consider each type available and acquire the one that is best for the child.

There are those individuals who really like cool vests. One frequently mentioned reason is peace of mind; knowing that you can go anywhere and not have a problem, unless the equipment itself fails. And there are those people who really do not like them.

Here, the reasons seem to center on a desire not to attract additional attention, concern that a child will become cool vest dependent, and that cheaper, equally effective and less cumbersome cooling methods are available.

If a spray bottle will enable a child to participate

in activities, find one of a size and shape that will accommodate that need. If family travel includes an automobile ride on a hot summer's day, go prepared for any eventuality.

There are lots of choices and alternatives for cooling. Base your cooling decisions on your child's needs and the best solutions to meet them.

Where Can I Purchase Cooling Products?

The Internet is a terrific resource for locating companies that sell cooling systems and products. The NFED also has a list of companies which provide these products.

What Other Useful, Cooling Products Are Available?

Families learn to be alert for the development of new cooling products. As technology improves, so does the availability of useful products. Search on the Internet to learn more about these cooling products and others:

- water bottles
- spray bottles with battery activated fans
- hats/visors/bandanas with gel packs inserted
- fanny packs
- cooling blankets
- neck wraps
- wrist wraps
- cooling vests

The content of this document is for informational purposes only. Questions regarding specific patient issues should be directed to the appropriate professionals for resolution.