

Cooling Information

Within the 150 different ectodermal dysplasia (ED) syndromes, the inability to perspire is a feature of many of the conditions. Since people who are unable to perspire can overheat, precautions should be taken to prevent over-heating or to cool the body if necessary. The following information provides answers to common questions on cooling needs, methods and products.

Does the need for cooling change over time?

Families experienced with ED tell us that the greatest difficulty with the heat seems to be present in younger children, those 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 ED indicate that changes at puberty included the ability to minimally perspire on the palms of the hands and soles of the feet. Whatever the reason, most children affected by ED learn to manage their inability to perspire as they age.

What are the signs of overheating?

It doesn't take long for a parent or carer to recognise when a child is overheating. Parents of children affected by ED 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.

Will children who can't perspire know whether or not they are hot?

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 seek out shade or use resources at hand. Some have sought the coolness of a linoleum or ceramic tiled floor by laying on it. Some kids wear dampened shirts or caps, some carry squirt bottles, and others plan their activities to limit risks on days with very warm temperatures.

There are families who choose to visit amusement parks or zoos on cloudy days - often the 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 trips as a precaution. 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.

Can children affected by the hypohidrosis (the inability to perspire) participate in sports?

Here, too, the answer is "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. Allowing the child 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 ED live in every state and probably every country on the globe. People living near deserts or in the warmest of climates have successfully accommodated any cooling needs.

Has brain damage occurred because of overheating?

The quick answer is "yes". But it is important to note that in those situations, the damage apparently occurred as a result of accompanying illness and the number of such incidents is extremely small. Several children (at this writing, less than 5 in 3,000) have sustained very high fevers in conjunction with illnesses and have suffered serious side effects. Both physical and or mental development can be adversely affected in such situations. However, we have no evidence that supports similar problems resulting from typical childhood activity of participation in sports. In fact, in our experiences, there has only been one instance where an individual found himself in serious need of aid as the result of rather routine activity. In that particular situation, a teenager's moped had malfunctioned on a hot summer's day. After pushing the vehicle in the heat for a time, the young man sought refuge in the shade. Ultimately a passer-by lent a helping hand. The teen had no cooling gear with him (not a good idea) but found relief in an air-conditioned room where he quickly recovered.

When outdoor temperatures escalate, be prepared.

Take a thermos of cool drinking water and cooling water or a squirt bottle in the car just in case it is needed. Plan out-of-door activities on days when risks can be minimized. Access to shade and water is always helpful. If your child is an athlete, you may find taking a golf umbrella, damp towels in a cooler, and a squirt bottle to be useful. It doesn't take long for active athletes to discover that a cool squirt of water on the head or a damp towel around the neck brings quick relief. Others soak their hat or shirt in water. Very often others with the ability to perspire begin to bring similar gear to athletic events as they, too, learn the benefits of keeping cool.

Don't take unnecessary risks.

Trips in unair-conditioned cars on warm days are not appropriate. The same is true for activities that require lengthy out of door exposure with limited or no access to cooling. Use good common sense and you will get through each warm day just fine.

Should the child's school be air-conditioned?

The effects of warming on the body of those who cannot perspire are such that performance at school and at work can be adversely affected. As indicated previously, irritability and lethargy are common effects, which can inhibit performance. Schools are required by public law to provide special education related services for those with disabilities. While that seems rather straightforward, school administrators and school boards are sometimes reluctant to provide what to many is a luxury. However, the need for air-conditioning can be well documented and should be provided to assure that those affected by ED can function appropriately.

Begin by talking with the school Head Teacher to determine the procedure you must follow. Do this well in advance (at least nine 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 EDS office.

Cooling Products - What are 'cool suits'?

'Cool suits' would more properly be called 'cool vests'. There are several different types, all of which consist of a product that can be worn on the torso and in some cases, the head as well. Generally, they are vest-like in design. Some include a coolant that is circulated through the garment by a battery-operated power pack. Depending on the size of the pack, anything from a luggage carrier to a small camera bag may be needed to transport the cooling system. These suits weigh anywhere from eight to about twenty pounds and price varies widely from a relatively nominal amount (100 British Pounds)) to thousands of pounds (2,500+ British Pounds). While these products may not be conducive to use in the midst of a football game, they can be helpful at other times. Another group of suits has a different cooling mechanism. These products contain packs that are frozen and then inserted into the vest. These vests are often lighter in weight and allow for greater mobility as compared to suits, which use a pumping system. These are much less expensive than those vests previously mentioned. Most cooling vests are custom made for the wearer to ensure proper fit.

Are cool vests used all of the time?

Generally the bulkiness of most cool vests make 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 ED. However, they can be quite useful in certain special situations, i.e. lengthy bus rides on unair-conditioned buses, for highway construction workers, as a means of portable cooling for athletes, etc. Familiarity with the various products available will enable each family to make cooling decisions, which are best for them.

Where can I purchase cool vests?

EDS office and the NFED have many addresses of Companies who produce these vests. Please contact either of them for more information.

Is a cool vest appropriate for my child?

A parent's responsibility is to provide for a child a method of cooling which is appropriate for that particular individual. 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 don't like them.

Here, the reasons seem to centre on a desire not to attract additional attention, concern that a child will become cool suit dependent, and that cheaper, equally effective and less cumbersome cooling methods are available. If a squirt bottle will enable a child to participate in activities, find one of a size and shape that will accommodate that need. Or if family travel includes a car 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.

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. There are many inexpensive cooling products available such as battery operated cooling mist dispensers, gel packs, head/neck bands containing water absorbing crystals which can be reused many, many times, etc. Again, EDS office and the NFED have many addresses of Companies who produce these products. Please contact either of them for more information.

What's the best cooling method?

Cooling is a necessary component to the lives of those who are unable to perspire. There are many ways to keep cool. Only you and your child know which choice is the best choice for you.

With the kind permission of the NFED this article has been taken from their "Cooling Information" leaflet

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