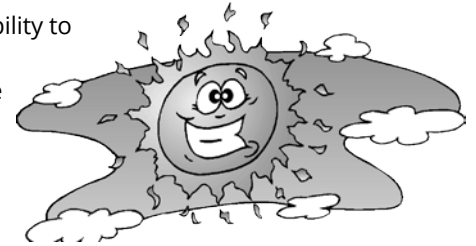


Cooling Tips

In the more than 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 overheating or to cool the body if necessary. The following information provides answers to common questions on cooling needs, methods and aids.



Does the need for cooling change over time?

Families experienced with ED have said 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 to recognize 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, unco-operation, bad behaviour and lethargy may follow. More serious situations can be accompanied by dizziness and/or nausea and may serve as a precursor to heat stroke.

Nosebleeds!

These appear to be a common occurrence for ED individuals when the weather is hot, particularly at night. A nosebleed can be scary to get - or see - but try to stay calm. Most nosebleeds look much worse than they really are. Almost all nosebleeds can be treated at home.

Place a cold compress (wet flannel) or an ice pack across the bridge of the nose whilst at the same time place a cold wet flannel on the back of the neck as this will help slow the blood flow. Once the bleeding stops, don't do anything that may make it start again, such as bending over or blowing your nose.

Are nosebleeds serious? Most aren't. Most nosebleeds occur in the front part of the nose and stop in a few minutes. You may need to get medical attention if a nosebleed goes on for more than 15-20 minutes.

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 learn helpful cooling techniques. It's amazing how they will seek out shade or use resources at hand. Young sports players have sought the shade of a tree in the sports field, toddlers have used ice pops for head coolers, and others have sought the coolness of a linoleum/ceramic tile floor by laying on it. Some kids wear dampened shirts or caps, some carry spray 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 outings 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.
School or Scout camps sheet

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

Here, too, the answer is "yes". The ED Society has ample evidence of individuals who have successfully participated in athletics including football, basketball, athletics, 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. A bucket of water on the touch line, wet t-shirt, spray bottle, drinking water, wet hat are all that are needed to enable them to join in sporting activities.

When outdoor temperatures escalate, be prepared.

Take a thermos of cool water and spray bottle in the car just in case it is needed. Take spare bottles of water in the car for pouring over you/your child, even if you have air-conditioning – just in case the air-con breaks down. Plan out-of-door activities on cooler days when risks can be minimized. Access to shade and water is always helpful.

If your child is a athletic, you may find taking a golf umbrella, damp towels in a cool box, and a spray bottle to be useful. It doesn't take long for active athletes to discover that a cool spray of water on the head or a damp towel around the neck brings quick relief. Others soak their hat or shirt in water.

Keep the fan on all through the night, preferably directed at the child's head

Put an ice pack under the child's feet at night, to help them stay cool or a cold damp cloth around their neck; this will help them settle better.



Don't take unnecessary risks.

Trips in an air-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.

What are "cool vests"?

There are several different types, all of which consist of a product that can be worn on the upper body and in some cases, the head as well.

Jackson Technical Solutions explain about Cool Vests

When wearing this "constant temperature 10C" cool vest, you should notice a reduced sweat rate, and in some people, reduced heart rate and blood pressure also occur.

Reducing your sweat rate means forfeiting less electrolyte fluids (retaining a suitable balance of valuable minerals required for proper muscle and neurological function) for later in your workday. Consequently you should feel more energetic and vigilant overall.

The Cool Vest is anatomically designed and one-size will fit all body types. The vest comprises a rugged, washable Nylon carrier with two cool packs. The vest is adjustable for all body types, at the shoulders for torso height, and around the mid-chest with adjustable elastic straps which provide a snug fit that enables high cooling efficiency with complete freedom of movement.

The cooling duration of the packs will vary depending on the person wearing it, the activity they are taking part in and the ambient air temperature.

The packs are easy to energise, maintain and store. Following this basic guide, and with proper care, the packs should last for many years.

Energising

All the cool packs can be energised in a domestic fridge or freezer in approximately 30 minutes. They can also be energised in a cool box, or any other environment, which is colder than the temperature the pack is set at (typically 10°C or 25°C), including for example, an air conditioned room. When being energised, the packs should be as flat as possible, to allow for easy insertion into the carriers.

Using the Vests

Once the energised packs have been inserted into the carrier, the carrier should be adjusted at the shoulders and mid-chest to ensure a snug but comfortable fit. The packs are initially stiff when the vest is first put on, but as they start to work, they will begin to soften and mould to the wearer.



Using the Seat

As the energised packs are fitted into the seat, they will also feel quite stiff. But as you start using the seat, it will begin to soften and mould to suit the way you sit on it. It will become comfortable within a few minutes of use.

All of the packs will need to be re-energised once all of the white solid has become clear fluid. As long as there is a small clump of white solid remaining (about the size of a 5p piece) the pack is still working. When less than that is left, it should be re-energised.

The packs can be stored in a fridge, freezer or cool box so they are ready for use at any time.

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.



The Helmet Cooler aids cooling by absorbing excess heat that builds up within headgear (micro-environmental temperature), reducing this temperature by 20-25 degrees or more, depending upon the situation. By substantially reducing this micro-environmental temperature, the head can expel more heat and accelerate the body's ability to naturally cool itself.

The Cool Zone Helmet Cooler's preset temperature does not deliver the cold sensation that you would expect to feel when you pick it up. Its higher temperature provides adequate energy to absorb excess heat that builds-up within the helmet, hardhat or other fixed headgear. The higher temperature provides longevity for the wearer, yet does not produce condensation on the head and face, as would a much colder device. Cold temperatures are not tolerated well by the human body and can produce negative reactions such as pain, cold shock, superficial vasoconstriction, discomfort and headache.

Bump Cap Cooler

The Cool Cap insert is placed in a baseball cap or bump cap and is effective in any hot weather condition even with 95% humidity. The material used in the cool pack is antimicrobial so it does not support bacteria or fungus growth. The

insert acts as a heat sink, removing excess body heat making the user more comfortable, reducing dehydration and maintaining energy.

The Cool Cap lasts 2+ hours and can be recharged in minutes by simply placing it in cold water or by leaving it in any air conditioned environment.



If you require any further information please contact us on 0845 644 3171 or visit our web site www.jt-solutions.com Jackson Technical Solutions Ltd, 4 Upper Cliff Road, Gorleston, Norfolk NR31 6AL or email: info@jt-solutions.com.

The "Chillow"® Pillow

"The Chillow ® is designed to keep your pillow cool. Turning over the pillow in search of a cool spot is history. This device produces a lasting, cool and comforting sensation without blowing air, making noise, or costing money to operate. There is no other product like it on the market. The soothing, relaxing effect will give you superior sleep night after night. Never too hot, never too cold... the use perfectly comfortable. It is a flexible, leak proof, cushioned pad that provides unique support regulating characteristics not present in dry foam, gel filled or basic water-filled products. Traditional pillows trap hot air and heat from the head. This makes most people uncomfortable and prevents them from getting a good nights rest. Once you have used it, you will never want to be without it and children love it.



The common ice or gel pack is freezing cold, hard, wet, and lumpy. Enter Chillow ®: a soft, flexible, dry, memory foam comfort solution. Cool at room temperature, Chillow ® may be refrigerated for extra cooling power and longer lasting comfort, but must not be put in the freezer.

Use the Chillow ® and you will never again long for a cool spot. Whether it's your pillow or your back, the soft cooling sensation will create comfort you can't resist. Patented Comfort Technology provides a unique fluid-cool, cushioning memory foam effect that is steady and long lasting. It requires no electricity and offers a noiseless, low cost cooling alternative that while dry itself, will not dry out the air around you or become too cold like traditional cooling methods. The Chillow ® is only activated one time for long term use. It is a non-toxic, non-gel product that is soft, and is manufactured to medical grade standards. It fits standard pillows and while it needs no refrigeration it can be refrigerated for an extremely cold sensation, but must not be put in the freezer.

How The Chillow ® Works:

The radiator works to keep your car's 250 Degree engine cool by using water to help dissipate heat to the air. Hot fluid enters the radiator, loses its heat, and cool water travels back through the system to begin the process again. The Chillow ® acts as a radiator for your body. It uses water to absorb, and then dissipate heat back to the surrounding air, leaving a cool sensation. It stays dry on the outside, and does not need refrigeration.

The Chillow will warm up closer to your body temperature after about 1.5 hours, by which time you should be asleep! In the morning ensure that the air can fully circulate over the Chillow ® and it will return to its normal coolness after an hour. The Chillow ® will be approximately 15 degrees cooler than the ambient temperature."

Obtainable from Amazon – don't forget to go to the www.ectodermaldysplasia.org and click on the Amazon link on the righthand side to ensure the ED Society receive commission.

Supporting a normal lifestyle

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