

Summary - Cool Ideas for Adults and Kids with Heat Intolerance

Maggie Orr, RN MSN EdM

What is heat intolerance, dysautonomia, and why is it such an important issue for people with mitochondrial disease?

Heat intolerance is a very common and troublesome symptom often associated with dysautonomia ([learn more](#)). As discussed with Dr. David Holtzman, pediatric neurologist at Massachusetts General Hospital, dysautonomia is the key to some of the most distressing symptoms that mitochondrial disease patients might experience. The autonomic nervous system is responsible for controlling many functions such as body temperature, maintaining blood pressure when sitting or standing, digesting food, and regulating other body functions that occur without conscious effort or awareness. It is very common for people with "Mito" to experience abnormal regulation of body temperature. One might have abnormal baseline body temperatures, inefficient or excessive sweating, inability to tolerate heat or cold.

MitoAction asked Maggie Orr, RN MSN EdM, Medical Advisory Board Member to join us to collaborate about heat intolerance and its causes. Maggie is the nurse coordinator in the Metabolism Service at the Floating Hospital for Children at Tufts Medical Center. She trained as a Family Nurse Practitioner at Yale School of Nursing and did primary care before staying home to care for her daughter, Mamie Rose, who died of mitochondrial disease (Complex I defect) in 2003. She has undergraduate degrees in Spanish and Early Childhood Education from Arizona State University, and a master's in education from Harvard Graduate School of Education.

Maggie explained that Mito patients often find that hot weather worsens all of their autonomic symptoms, such as flushing, pallor, irregular heart rate, and even gut dysmotility. Hot weather can also worsen non-autonomic symptoms such as seizures, muscle pain and cramping, fatigue, and behavior (irritability, hyperactivity, non-compliance, etc.). In short, it is very common for the person with mitochondrial disease to "wilt" in the heat like a delicate flower needing to be watered!

Maggie's emphatic advice as the cornerstone of managing not only heat intolerance but many other issues associated with mitochondrial disease is to "Know yourself or your child, and plan ahead". Recognizing one's tolerance levels for outdoor temperatures, indoor/outdoor humidity, activity levels, and planning for the necessary recovery time is absolutely crucial. To complicate the equation, incorporating other factors such as infection, dehydration, etc. may increase the recovery time and decrease the tolerance threshold. Many parents, spouses, and adults who live with mitochondrial disease understand the challenges of "unpredictability" in managing mitochondrial disease.

Minimize outdoor exposure in warm weather, and be prudent in planning for vacations (i.e. don't go to Disney in July!) and trips. Recognize the increased energy demand that heat creates for any individual with a mitochondrial disorder. Fluids (including fruits and vegetables) are critically important in warm weather, as are the other cornerstones of Mito management, nutrition and rest.

How can we help the body to stay cool? Air conditioning, misting the skin with water and using a fan are simple strategies to cope with the heat. In addition, use of a cooling vest may aid a person to keep a stable body temperature by using evaporative techniques. MitoAction invited founder Nancy Keen of Silver Eagle Outfitters to join us and share insider tips about using a cooling vest.

Cooling vests have been used by industries requiring individuals to withstand desert temperatures and by people in hot southern climates, and may have a benefit to patients who have difficulty in the heat. Nancy expressed her desire to help adults and kids to have more freedom and better quality of life by being able to spend more time comfortably and safely outdoors. Cooling vests work by using nature's perfect cooling system - evaporation. A cooling vest absorbs a small amount of water before use and cools the body while the person is wearing by pulling excess heat away from the body as the water evaporates out of the vest. The lightweight vest is only slightly damp - not wet - and can be worn on top of or under a light shirt. The vest, unlike ice or something very cold directly on the skin, does not "feel cold" but rather helps to regulate body temperature by removing excess heat.

Humidity is an important factor to consider, as sweating as well as cooling vests operate on the assumption that moisture can evaporate from the skin, taking excess heat with it. If the air humidity is above 85%, there is no way for that evaporative cooling to occur. Air circulation, humidity as well as the actual temperature are all factors to consider.

Silver Eagle Outfitters customized many cooling vests for children with mitochondrial disease over the last year, and is even able to create an opening and a pouch to accommodate a g-tube and formula. "Measurements are the most important way to be sure you get a good fit", says Nancy. Silver Eagle Outfitters can be reached on the web at <http://coolingapparel.com/> or by phone at 1-888-692-6763. A vest may cost between \$55-\$100.

Please share your ideas and strategies to keep cool!

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