

Put off by going to theme parks because the queues could cause your child to overheat.

If you read the disclaimer section of some theme parks for example Legoland you may find it reads like this under the disability section:

"Ride Access Passes are reserved for guests who do not understand the concept of queuing; have difficulties with everyday social interaction; have a limited capacity to follow instruction or to understand others' emotional feelings of expressions, and may therefore become agitated or distressed if they had to queue for a ride for an extended period of time".

From the following explanation of your child's condition you will see that he/she qualifies under the last section of their disability eligibility.

The major and life-threatening symptom of Ectodermal Dysplasia is the total absence of any sweat glands whereby the sufferer can easily overheat leading to fits and ultimately death.

In a child with ED lack of temperature control even on days when the temperatures are considered normal, means that he can walk no more than a few yards in sunshine or on a warm day.

In addition to this ED Children cannot control his temperature in cold weather causing hypothermia to the point that it is also extremely dangerous for them.

Your child has non-functioning and missing sweat glands and is therefore unable to maintain a constant internal core body temperature leading to overheating at any time of year, either from atmospheric temperatures or an impending infection. If your child is not cooled down they will become tired and lethargic and eventually this will lead to a fit or worse death. Also, there are problems in the winter months in maintaining an adequate body temperature, i.e. if they get too cold and have difficulty in warming up, and when this happens they appear to be in a dream, not concentrating or listening.

One of the signs that an Ed child's temperature is too high is their behaviour. They become emotional, frustrated, anxious, un co-operative and throw themselves around. In many cases their skin temperature is absolutely no indication as to his internal core temperature. They can get extremely upset after overheating.

They also suffer with joint pain and muscle weakness.

From this you will see that it would be extremely difficult for them to queue for any length of time thereby making a happy exciting family outing into a nightmare and placing them into possible extreme danger.

Supporting a normal lifestyle

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