

Ectodermal Dysplasia and Covid-19

I hope you are all keeping well and safe during this really difficult time. I have five children who are all thankfully grown up now, but the thought of home schooling them for several months horrifies me. I take my hat off to all parents – keep going, be patient (not easy), stay strong and we will all get through this.

I thought I would explain a little about ED and Covid-19.

Symptoms of Ectodermal Dysplasia include abnormalities of nasal and respiratory mucous production, and some individuals experience asthma, recurrent ear and chest infections.

The linings of the nose, larynx, trachea and lungs are moistened by various glands, some of which may be absent, reduced in number or not functioning normally. The nasal mucous may be much thicker than normal, forming a crusty mass. The underproduction of respiratory fluids together with constant nasal congestion can cause frequent infections for which antibiotics may be necessary.

Individuals affected by ED and those with added immune deficiency are at increased risk of more severe respiratory infection, including pneumonia, with COVID-19 compared to the general population. Therefore, there is likely an increased risk of more severe infection involving the lungs with COVID-19 infection in these individuals.

It may be helpful to have a humidifier in the bedroom at night to help moisten the air which will help keep the respiratory tract and nasal passages moist.

Another common feature of ED is impaired temperature control. Individuals affected by ED have a reduced ability to sweat due to absent or reduced sweat glands and can therefore overheat at any time of year, especially due to an impending infection.

The lack of temperature control for many individuals affected by ED is a worry during this time. Be vigilant regarding temperature, the average body temperature is 37°C (98.6°F). Some studies have shown that the “normal” body temperature can have a wide range, from 36.1°C to 37.2°C. A temperature over 38°C (100.4°) most often means you have a fever caused by an infection or illness.

Individuals affected by ED have a wide range, sometimes as low as 35°C. It is therefore important to know the normal average temperature of an individual affected by ED in order to know the level of increase. Therefore, a “normal” temperature of 36°C that rises to 38° is a potentially dangerous level.

If you have a raise in temperature it is important to use the normal cooling tips we provide on our website and seek medical help. You may like to take this article with you to the doctor/hospital to explain the difference between an individual affected by ED and those unaffected.

Remember, follow the Government guidelines, go with your gut feeling, you know yourself and/or your child better than anyone.

I am happy for my mobile 07774 465712 to be given to your doctor, nurse or other care provider.

Stay safe.

Diana Perry (CEO)

Supporting a normal lifestyle

Ectodermal Dysplasia Society (Registered Charity No. 1089135). Disclaimer: Any views or opinions are made by the author in good faith. No liability whatsoever is accepted by the author or the Ectodermal Dysplasia Society. Recipients should make their own additional enquiries of medical and other relevant authorities before acting on these views. The use of a product name does not constitute a recommendation or endorsement by the author or the Society.