

## Ectodermal Dysplasia and Covid-19

The Government and NHS list of diseases and conditions considered to be very high risk includes people with rare diseases (item 4 group 1).

The NHS has written to people considered to be at highest clinical risk from coronavirus (COVID-19) to inform them that they should stay at home at all times and avoid all face-to-face contact for a period of at least 12 weeks.

Many of our members have contacted their GP as they have not received an NHS letter. This is because they are prioritising those at highest risk, so you may still receive a letter.

If you feel you or a member of your family fall into the high risk category then it is highly important you follow the stringent Government guidelines on self-isolating and, handwashing and respiratory hygiene.

There are general principles you should follow to help prevent the spread of airway and chest infections caused by respiratory viruses, including:

- wash (scrub) your hands more often - with soap and water for at least 20 seconds or use a hand sanitiser containing at least 70% alcohol. Do this after you blow your nose, sneeze or cough, and after you eat or handle food
- avoid touching your eyes, nose, and mouth with unwashed hands
- avoid close contact with people who have symptoms
- cover your cough or sneeze with a tissue, then throw the tissue in a bin or cough, sneeze into your arm
- clean and disinfect frequently touched objects and surfaces in the home

**It is important for your GP or any hospital medical professionals to know the 'at risk' area of Ectodermal Dysplasia. I have therefore compiled this letter for you to hand to them.**

The major and life-threatening symptom of some of the syndromes of Ectodermal Dysplasia (ED) is the total lack of temperature control whereby the sufferer can easily overheat leading to fits and ultimately death.

The impaired temperature control for many individuals affected by ED is caused by absent or non-functioning sweat glands.

As this is such a worrying 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 there is a raise in temperature it is important to use the normal cooling tips provided on the ED Society website and seek medical help. **This letter can be taken to the doctor/hospital to explain the difference between an individual affected by ED and those unaffected.**

Other symptoms of ED which may cause problems associated with Covid-19 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 in those affected by ED and not drain in the

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normal way, forming a crusty mass and making breathing difficult. Missing or non-functioning respiratory glands cause an underproduction of respiratory fluids which, together with constant nasal congestion, can cause frequent infections.

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.

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

Stay safe.

**Diana Perry**  
**CEO**