

18th March 2021

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

Some carers are now included on the vaccination priority list in group 6. Those who are eligible for a carer's allowance, or those who are the sole or primary carer of an elderly or disabled person who is at increased risk of COVID-19 mortality and therefore clinically vulnerable, should be offered vaccination in priority group 6, which includes unpaid carers. Make sure you are registered as a carer with your GP.

The JCVI (Joint Committee on Vaccination and Immunisation) has included eligible unpaid carers on the vaccination priority list (UK wide) in group 6. In the list of eligible groups it states "At the same time as the adults under 65 years with long term conditions, the vaccine will also be offered to:

- adults who provide regular care for an elderly or disabled person.

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.

Supporting a normal lifestyle

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 2 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