ESPE Patient Information on COVID-19 and Pediatric Endocrine Diseases

Disease specific information and advice: Endocrine Tumour Syndromes (includes MEN, Phaeochromocytoma-Paraganglioma, PTEN and VHL)

This flyer aims to provide guidance on prevention and treatment of COVID19 in patients with a pediatric endocrine disease. It summarizes fast facts about COVID-19, and what children with endocrine diseases and their parents need to know regarding their health and well-being. These recommendations are based on the latest knowledge and expert opinion. Please note, this list of Tumour Syndromes is not exhaustive. If, after reading this, you still have concerns or questions, please contact your physician or healthcare provider.

What is COVID 19?

COVID-19 is the term used to cover infection with a specific novel coronavirus named SARS-CoV-2. On March 11 2020, WHO publicly declared COVID-19 as a pandemic. People who are confirmed to have COVID-19 have exhibited mild to severe respiratory illness with fever, coughing and shortness of breath. Additional symptoms can include loss of smell, muscle pain or fatigue. Other less common symptoms include headache, sore throat and gastro-intestinal symptoms (nausea, vomiting, abdominal pain or diarrhea).

Symptoms may appear 2–14 days after exposure to the virus. Risk on severe course of COVID-19 is associated with increasing age, being overweight or obese, male gender, black or minority ethnicity, high blood pressure and diabetes.

It is important to note that over 80% of infections are not severe and most patients recover without hospitalization or special treatment. This is particularly true in children and young adults.

Children and COVID 19

Data on children infected with COVID-19 remains scarce, partly because children seem as a group to be much less severely affected that adults. Few children require hospitalization and deaths from COVID-19 in people under 19 years is extremely rare. Many children with COVID-19 have no symptoms.

A large review of all young people infected with COVID-19 from 21 European countries was recently published in the Lancet (June 2020). 585 children were included in the study – 25% of which had pre-existing conditions (most usually underlying lung disease or immunodeficiency). The majority (87%) did not need any additional supportive treatment (e.g. oxygen). 4 (0.69%) patients died - 2 of which had severe pre-existing medical conditions.

Are children with Endocrine Tumour Syndromes (ETS) at increased of coronavirus?

There is no evidence that young people with an ETS are more likely to be infected with COVID 19 or have a more serious illness than children who have no underlying health condition.
For those children who have had adrenalectomy and are on steroid replacement therapy – we know that children with adrenal insufficiency are at higher risk from any infection in general, there is no evidence that they are at increased risk of acquiring coronavirus and the most recent June 2020 data supports this. Please also see the separate ESPE leaflet on coronavirus and adrenal insufficiency.

If a patient with adrenal insufficiency becomes infected with the coronavirus as with other infections there is a risk of an adrenal crisis developing. You should ensure you have plenty of supplies of hydrocortisone tablets or granules and your emergency injection of hydrocortisone. If your child has signs of coronavirus infection (cough, fever, shortness of breath) you should follow the sick day guidelines you have been given from your paediatric endocrinologist about increasing hydrocortisone dose – usually this is double or triple the usual dose given three or four times daily. If your child is unable to swallow or vomits the hydrocortisone tablets or is becoming worse despite the increase in dose you should administer the emergency injection of hydrocortisone and seek urgent medical care.

**How to protect yourself from COVID 19?**

At present, there is no vaccine for COVID-19 but there are a number of measures we can all take to reduce the spread of infection. These include:

- Social distancing as per local government advice
- Limiting social gatherings as per local government advice
- Handwashing with soap and water for at least 20 seconds if you have been outside your home and trying not to touch your face/mouth/nose with unwashed hands
- Avoid close contact with people who are unwell and to stay at home when you are unwell
- Disinfect frequently touched objects and surfaces

In addition, be prepared – have your doctor’s contact details and know who to contact in an emergency or out of hours

**Do coronavirus prevention measures differ for children with ETS compared to the general population?**

The coronavirus precautions are no different for children with ETS than for healthy children. No additional precautions are needed other than the usual advice. They should go to school when permitted by the general coronavirus prevention measures. The coronavirus will be around for a long time; therefore, it is important for children to attend school regularly to allow for their education, as well as normal development and general well-being.

If you are recommended to have the flu vaccination normally, then it is encouraged you take this up as early as possible.

**What is the advice on the regular monitoring of children with Endocrine Tumour Syndromes?**

Most children who are under surveillance due to having a predisposition to developing Endocrine Tumours are not on regular medication. However, if you are on medication such as steroids or thyroxine then this will need to be monitored as usual by your local endocrine team. Sometimes part
of the consultation might be via video or telephone rather than face to face but your child will need their bloods tests and scans done as normal to ensure everything remains OK.

You should ensure you have enough medical supplies to hand. This is particularly important for children with adrenal insufficiency as part of hypopituitarism as running out of medications for those conditions would be life-threatening.

**How do you look after your mental wellbeing?**

Understandably, your child may find that social distancing can be boring or frustrating. You may find their mood and feelings are affected and they may feel low, worried or have problems sleeping and you might miss being outside with other people.

At times like these, it can be easy to fall into unhealthy patterns of behaviour which in turn can make you feel worse. There are simple things you can do to help your child which include any activities that aim to keep them mentally and physically active during this time.

*Stay connected with family and friends*

Depending on the age of your child, you can draw on support you might have through their friends, family and other networks during this time. Try to encourage them stay in touch with those around them over the phone, by post, or online.

Encourage them to let people know how they would like to stay in touch and build that into their routine. They may find it helpful to talk to friends and family about how they are feeling.

**Summary**

In children, disease course of COVID-19 is generally mild, mostly they do not get sick or only short and mildly. The coronavirus measure for children with Endocrine Tumour Syndromes are no different to healthy children.

**Disclaimer:** Due to the emerging nature of the COVID-19 crisis this document is not based on extensive systematic review or meta-analysis, but on literature review and expert opinion. The document should be considered as guidance only; it is not intended to determine an absolute standard of medical care. Healthcare staff need to consider individual circumstances in their management for patients.

**References**


*Updated September 2020*