

**Cushing's management during COVID-19: Lay Summary of**  
**Expert Guidance published in the European Journal of**  
**Endocrinology**

**Prepared for HRA Pharma Rare Diseases**

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# What to Expect as a Person Living with a Possible or Confirmed Diagnosis of Cushing's Syndrome During the COVID-19 Pandemic

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## Introduction to the Guidelines

Many doctors use a set of instructions, known as guidelines, to help them look after people in their care. These guidelines are usually written by groups of experts, and are reviewed by other experts, before being published in academic journals.

During the COVID-19 pandemic, a group of international endocrinology experts were asked to write guidelines to help doctors look after people with a possible or confirmed diagnosis of Cushing's syndrome in their care. Due to the unprecedented nature of the pandemic, and although every person will be treated as an individual, the way in which people are treated will differ to the norm. The guidelines were published in the European Journal of Endocrinology in April 2020, and may be used by doctors, specialist nurses and other healthcare professionals.

This document explains these guidelines using non-medical language and will help people living with a possible or confirmed diagnosis of Cushing's syndrome, to understand what to expect during the COVID-19 pandemic, which is severely affecting medical services.

The guidelines are **only meant to be used during the pandemic**, when medical services may not be able to offer the level of care that people normally receive. The guidelines should be reviewed every 2 to 3 months from April 2020 in each country or region.

Care can vary depending on many things, including:

- Developments of the pandemic
- The severity of the virus outbreak in your area
- The way health services are organised in your country or region
- The way health services have adapted to cope with the pandemic

## **Guidelines for Caring for People with Suspected or Confirmed Cushing's syndrome**

### **Guidelines - Key General Points**

- If possible, consultations with healthcare professionals should take place over the telephone or via video calls.
- If face-to-face consultations are needed, healthcare professionals should be protecting you and themselves by wearing protective clothing.
- If you have diabetes and/or high blood pressure these need to be treated and controlled properly because having these two conditions increases the risk of you becoming more unwell if you get infected with COVID-19.
- If you need tests to decide on your diagnosis or treatment your specialist will adapt these to reduce your exposure to the COVID-19 virus. These tests may be different to those done under normal circumstances, particularly if you are having any scans, like ultrasound, CT, or MRI scans.
- Your medical team will probably assess your condition and its severity by phone or video consultation. Videos are better so that the healthcare professional can see you. Remember to mention everything, even if you do not think it is relevant. If you appear to have moderate or severe symptoms, you should have tests and treatment as soon as possible.
- If your Cushing's syndrome is stable and under regular review, your normal tests should be postponed to a later date when the restrictions in place due to the pandemic are over. You should still be able to have a consultation with your healthcare team by telephone or video call.
- Any care or advice that you are given should have been discussed by your healthcare team with regional/national experts in the management of Cushing's syndrome (unless you are already under the care of such a specialist).
- **You should always seek advice from your healthcare team if you have any questions about your Cushing's syndrome and/or you need extra reassurance about anything. Make sure you know how to contact them. The guidelines say that regular communication between you and your health care team is important.**

### **Guidelines - for Those with Suspected Cushing's Syndrome**

- Making a diagnosis of Cushing's syndrome can be challenging. The guidelines stress that healthcare professionals need to get a clear picture of what is happening to you in terms of signs and symptoms.
- You can expect to have some blood tests and scans organised. These will be arranged with appropriate precautions being taken according to local advice about COVID-19.
- If your diagnosis is uncertain, the guidance is that your clinical condition and evaluation should be repeated every 3 to 6 months or delayed until the pandemic is over.

- If it is decided to delay further tests and treatment, the guidelines recommend that you get prompt and effective treatment for diabetes and/or high blood pressure (if you have these).

### **Guidelines - for Those with Confirmed Cushing's Syndrome**

- If you have mild symptoms the guidance is that your clinical condition and evaluation should be repeated every 3 to 6 months or delayed until the pandemic is over.
- If you have active or severe Cushing's syndrome, you have a higher risk of getting an infection because your immune system does not work as well as it should. Therefore, it is important that you follow instructions from the government about things like hand washing, social distancing, and self-isolation/ shielding including taking sick leave. If you have any concerns about this, you should seek extra advice from the doctor responsible for your care.
- If the assessment shows that you have moderate or severe Cushing's syndrome, the recommendation is that you receive prompt investigation and treatment. This will reduce your risk of getting an infection or hospitalisation.
- Very occasionally, the Cushing's syndrome can be caused by a cancerous tumour. Therefore, your specialist may arrange for you to have a CT scan of your chest and abdomen. This will not only show if you have a tumour, but it can also help to identify complications of Cushing's syndrome such as small clots in the lungs, thin bones in the spine, and serious infections. The findings of the scan will help the doctor to decide which treatment you will get. Your doctor should explain all of this to you before the scan is arranged.
- You can expect to have some laboratory tests organised; the doctor will take some samples of your blood and you will be asked to provide a urine sample.
- If you need to have more extensive investigations or an operation, your specialist will explain this to you, though they will try to delay these as far as possible during the pandemic. This means that you will be treated only with medicines unless surgery is unavoidable.
- Occasionally with Cushing's syndrome, your vision may be affected. If this is the case, you will be sent for a CT or MRI scan, to see if your pituitary gland has got larger. Your pituitary gland is located at the base of the brain. If your pituitary gland has got larger then you may need urgent surgery.
- The advice in the guidelines reminds doctors to arrange these scans in such a way as to minimise the risk of you or your healthcare professional catching the virus.
- All other tests will be delayed until the measures introduced to combat COVID-19 have been relaxed.
- Once the restrictions have been lifted in your area, you can expect further tests to help determine the cause of your Cushing's syndrome. This will help doctors know which treatment you should receive. To do this, your specialist may temporarily stop some, or all, of your medication. Your doctor should explain all of this to you.

## **Guidelines - Treatment**

- The guidelines advise that all surgery should be avoided wherever possible to limit possible exposure to the virus, and this is of course true for surgery for Cushing's syndrome.
- However, there may be situations where the risks of delaying surgery are higher than the risks of surgery. Surgery will be suggested if treatment with tablets does not work or causes unpleasant side effects, if your eyesight is threatened, or if there is a cancer present.
  1. If immediate surgery is considered as a treatment, they may alter the way that the surgery is done, in a way that reduces the risk to you and your healthcare team. You should ask your doctor to explain the risks and benefits of this, and if the treatment decision is in line with the guidelines.
  2. In other cases where surgery might be the best long-term treatment for your Cushing's syndrome, it will be delayed until the risk of catching the virus has reduced.
- Many people with Cushing's syndrome will either already be on or will start treatment with various medications including cortisol lowering tablets. For those already on medication, it may continue for longer than usual, and could vary dependant on where you live. This medication will help:
  1. Reduce the level of natural steroids in your blood. There are several available drugs to help do this, and your doctor should explain them to you. In some people, more than one drug will be required to control the blood steroid level. If you are already on medication, this might be altered so fewer follow up appointments will be needed.
  2. High steroid levels result in your immune system not working as well as it should. Therefore, antibiotics may be given to reduce this risk.
  3. You may require treatment for a low potassium level in your blood, and as high levels of blood steroid levels can cause small blood clots to form, injection of a drug known as "low molecular weight heparin" will be prescribed to reduce this risk.
  4. If you have high blood pressure and/or diabetes these will be treated with medication.

### **Guidelines - Monitoring**

- You should expect to have some regular tests to see how you are doing, to ensure that your Cushing's syndrome is under control and that there are no side effects from your medication. You will be asked to have blood tests and to provide urine samples, and your consultations will almost certainly be done via telephone or video conferencing.
- You may have to monitor your own weight, blood pressure and blood glucose levels at home.
- As a result of this monitoring, changes may be made to your treatment—usually an alteration in the dose or a change of the type of medication. This will help to control your disease and help you stay well until things return to normal.

### **Guidelines - Summary**

- You must follow any advice on practical steps to reduce the risk of catching COVID-19 such as hand washing, self-isolation, and social distancing.
- Your contact with your healthcare team will be mainly on the telephone or video link to limit trips to hospital. You will be followed up every 3-6 months until things return to normal.
- Laboratory tests, scans and surgery will be kept to a minimum to avoid possible exposure to the virus.
- If you have an uncertain diagnosis or have mild symptoms, your team will wait until things return to normal before any changes are made to the way that you are treated.
- If you have moderate or severe disease you may need to have extensive tests and/or surgery. These will only be done if necessary and all steps will be taken to reduce the risk of transmitting the virus.
- The doctor treating you will be in touch with an expert in Cushing's syndrome (if they are not an expert themselves).
- Unless urgent surgery is needed, you will be treated with medication aimed at normalising cortisol levels to reduce symptoms and the risk of complications, until such a time as it is safer to have surgery.
- If you have a diagnosis that cancer has caused the Cushing's syndrome, then your doctor will assess whether the benefits outweigh the risks of surgery during the pandemic.
- If you have co-existing conditions such as diabetes and high blood pressure these will be treated appropriately.
- Once health services have returned to normal, further tests may be required and treatment might be adjusted to something more appropriate for the long term.
- You should have education in, and access to, the use of emergency stress doses of steroids.
- It is important to be in regular touch with your healthcare team as communication is always key.

**IMPORTANT ADDITIONAL INFORMATION**

**Make sure that you know about your personalised emergency regimen, and how to contact your healthcare professional in case of an emergency or even a routine question.**

If you have any questions relating to this guidance, please contact your healthcare professional.

For further information on Cushing's syndrome, please visit The Pituitary Foundation:  
<https://www.pituitary.org.uk/>

For further information on current COVID-19 guidance in your country please visit Gov.UK :  
<https://www.gov.uk/coronavirus>

The full guidelines can be found at:

<https://ej.e.bioscientifica.com/view/journals/eje/aop/eje-20-0352/eje-20-0352.xml>