

# Increasing your hydrocortisone to prevent an Addison crisis

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**This folder explains how you can prevent an Addison crisis (also known as an adrenal crisis) by increasing the dose of hydrocortisone yourself. This can be necessary in situations that cause you physical or mental stress.**

**This folder is a supplement to the information that you have already received from your own doctor. In the Dutch version of this folder we refer to these recommendations as ‘stress instructions’; some patients may notice that they are very similar to ‘sick day rules’ but we have opted not to use that term. If you have any queries after reading the folder, please get in touch with your doctor or the nursing staff on the ward.**

**Why are stress instructions necessary?**

Because you suffer from adrenal insufficiency, your adrenal glands don’t produce enough cortisol. That is why you have to take hydrocortisone. This medicine corrects the cortisol level.

In a stress situation, however, your body needs more cortisol. Stress situations could be illness, an accident, an operation or mental stress. In such cases, you need to increase the dose of hydrocortisone that you are taking. If you don’t take enough medication, there is a risk that you will suffer an Addison crisis. This is a life-threatening situation that arises because of a serious shortage of cortisol.

In the ‘Guidelines for taking hydrocortisone to prevent an Addison crisis’ you can read when you should increase the dose of hydrocortisone, and by how much. You will also read when an emergency injection with hydrocortisone (usually in the form of Solu-Cortef®) should be administered and when you should contact your endocrinologist.

**What are the symptoms of a shortage of cortisol?**

When your treatment with hydrocortisone is well-adjusted, most of the symptoms arising from adrenal insufficiency disappear or at least decrease. If your body’s demand for cortisol increases and the dose is not increased accordingly, symptoms of a cortisol shortage can reappear or worsen. The milder symptoms of a shortage of cortisol are:

This folder is intended for patients with adrenal gland disorders who live in the Netherlands; it will also be useful for their carers and the medical practitioners who treat them (GPs, specialists and nurses). It was first published online in the summer of 2016.

It has been translated so that patients and medical assistance providers from other language areas and other countries can become familiar with the procedure that was recommended in the Netherlands at the time of publication – summer 2016. It is not the intention of the authors that this document should be seen as a standard for adrenal patients outside the Netherlands. If you have any queries about the contents of this document, please get in touch with the medical practitioner/specialist who is treating you.

- tiredness
- concentration problems
- muscle weakness
- feeling gloomy
- loss of appetite
- dizziness

More severe symptoms of a shortage of cortisol are what we call an Addison crisis. In the following paragraph you can read how you can recognize an Addison crisis.

**How can I recognize an Addison crisis?**

An Addison crisis occurs when there is a sudden worsening of the cortisol shortage. An Addison crisis can occur with all forms of adrenal insufficiency. When an Addison crisis is looming, the shortage of cortisol can occur suddenly or more gradually. It can be brought on by some form of severe physical or mental stress. If the right action is not taken, an Addison crisis can also occur in a situation with only moderate stress.

The most common symptoms of an Addison crisis are:

- nausea and an odd sensation in your stomach
- vomiting
- stomach ache and diarrhoea
- fever
- sleepiness, drowsiness, weakness, feeling faint

## Guidelines for taking hydrocortisone to prevent an Addison crisis

<p><b>Slight physical stress, for example:</b> Playing a sport intensively</p>	<p><b>Adjustment to dose of hydrocortisone</b> It could be necessary to adjust the dose of hydrocortisone. Discuss this with your endocrinologist.</p>
<p>Mild symptoms of illness (e.g. common cold), body temperature under 38.0°C/100.4°F</p>	<p>You do not need to adjust the dose unless you know from experience that extra hydrocortisone will help you recover more quickly. In that case, take an extra 5 to 10 mg of hydrocortisone a day for a short while. If you wish, you can spread this extra dose over the day.</p>
<p><b>Moderate physical stress, for example:</b> Increasing symptoms of illness and/or temperature between 38.0° and 39.0°C/100.4 - 102.2°F Vomiting a few times during illness Having diarrhoea for a short time during illness</p>	<p><b>Adjustment to dose of hydrocortisone</b> Take an extra 20 mg of hydrocortisone straight away. Double the daily dose of hydrocortisone throughout the day (morning, afternoon and evening), taking at least 20-10-10 mg of hydrocortisone during a day. Do this for as long as you feel ill. If you have a fever for more than 48 hours, get in touch with your GP. Mention that you have adrenal insufficiency.</p>
<p>Dental treatment</p>	<p>Take an extra 10 mg of hydrocortisone one hour before the treatment.</p>
<p><b>Severe physical stress, for example:</b> Severe symptoms and/or a temperature above 39.0°C/102.2°F</p>	<p><b>Adjustment to dose of hydrocortisone</b> Take an extra 20 mg of hydrocortisone straight away. Triple the daily dose of hydrocortisone throughout the day (morning, afternoon and evening), taking 20 mg of hydrocortisone at least 3 times a day. Do this for as long as you feel ill. If you have a fever for more than 48 hours, or you are feeling really ill, get in touch with your GP. Mention that you have adrenal insufficiency.</p>
<p>Accident with injury</p>	<p><b>If in doubt: contact your endocrinologist.</b> Take 20 mg of hydrocortisone.</p>
<p>Persistent vomiting Persistent watery diarrhoea: once or twice an hour</p>	<p><b>If necessary: contact your endocrinologist.</b> <b>Inject 100 mg of hydrocortisone (Solu-Cortef®) into a muscle or under the skin. Contact your endocrinologist immediately afterwards.</b></p>
<p>Reduced awareness / Unconsciousness</p>	<p><b>Call the emergency number or get someone to call for you. Mention that you have adrenal insufficiency. Inject 100 mg of hydrocortisone (Solu-Cortef®) into a muscle or under the skin. Contact your endocrinologist or get someone to call him for you.</b></p>
<p><b>Moderate mental stress, for example:</b> Fear of the dentist Important or stressful exam or test Job interview</p>	<p><b>Adjustment to dose of hydrocortisone</b> You do not need to adjust the dose unless you know from experience that you will experience symptoms of adrenal insufficiency if you don't take extra hydrocortisone. In that case, take an extra 2.5 to 5 mg hydrocortisone a day just once. Evaluate this with your endocrinologist afterwards.</p>
<p><b>Severe mental stress, for example:</b> Death of a loved one Funeral Traumatic experience</p>	<p><b>Adjustment to dose of hydrocortisone</b> Take 20 mg of hydrocortisone. Then increase the daily dose (double it, for example) for a short while. This will depend on the level of stress.</p>

### How long do I have to keep taking the stress dose of hydrocortisone?

If you are ill, you should take extra hydrocortisone as set out in the guidelines above until you are better again. This means that you have no more symptoms of your illness and your temperature is back to normal. From that moment you can start reducing the extra dose. How you do that is explained in the next paragraph.

In the case of severe mental stress, the length of time you should take the stress dose will depend on the situation and the level of stress you are experiencing. For example: if a loved one dies, the moment when you hear the news can be very distressing and upsetting. In that case, take 20 mg of hydrocortisone straight away and double your usual dose for the rest of the day. On the next day, you can go back to the normal daily dose. But if you experience any symptoms of a shortage of cortisol, increase the dose and take at least 2.5 mg extra, or even take up to double the normal daily dose of hydrocortisone. On the day of the funeral you should again double the normal dose of hydrocortisone.

### How do I reduce the stress dose of hydrocortisone again?

If you no longer have a fever and/or symptoms of illness, you can gradually reduce the stress dose of hydrocortisone back to your normal maintenance dose. Do this over a period of two to four days, depending on the dose and the symptoms. While you are reducing the dose, take your hydrocortisone at the usual times.

If the total stress dose was 60 mg a day or more, then you should reduce it by 20 mg a day until you bring the daily dose down to 40 mg, then by 10 mg a day until you are back on your usual maintenance dose. If the total stress dose was less than 60 mg a day, you should reduce it by 10 mg a day until you are back on your usual maintenance dose.

#### *Example 1: patient with a normal daily dose of 15 - 5 mg of hydrocortisone*

Because of severe physical stress, the hydrocortisone dose is increased to 20 - 20 - 20 mg (i.e. 60 mg a day). Once the patient no longer has a fever or any symptoms of illness, he or she can start to reduce the dose:

day 1: 20 - 10 - 10 mg = 40 mg

day 2: 15 - 10 - 5 mg = 30 mg

day 3: 15 - 5 mg = 20 mg, maintenance dose

#### *Example 2: patient with a normal daily dose of 7.5 - 2.5 - 2.5 mg of hydrocortisone*

Because of severe physical stress, the hydrocortisone dose is increased to 20 - 20 - 20 mg (i.e. 60 mg a day). Once the patient no longer has a fever or any symptoms of illness, he or she can start to reduce the dose:

day 1: 20 - 10 - 10 mg = 40 mg

day 2: 15 - 10 - 5 mg = 30 mg

day 3: 10 - 5 - 5 mg = 20 mg

day 4: 7.5 - 2.5 - 2.5 mg, maintenance dose

#### *Example 3: patient with a normal daily dose of 15 - 5 mg of hydrocortisone*

Because of moderate physical stress, the hydrocortisone dose is increased to 20 - 10 - 10 mg (i.e. 40 mg a day). Once the patient no longer has a fever or any symptoms of illness, he or she can start to reduce the dose:

day 1: 20 - 10 mg = 30 mg

day 2: 15 - 5 mg = 20 mg, maintenance dose

#### *Example 4: patient with a normal daily dose of 10 - 5 - 5 mg of hydrocortisone*

Because of moderate physical stress, the hydrocortisone dose is increased to 20 - 10 - 10 mg (i.e. 40 mg a day). Once the patient no longer has a fever or any symptoms of illness, he or she can start to reduce the dose:

day 1: 15 - 10 - 5 mg = 30 mg

day 2: 10 - 5 - 5 mg = 20 mg, maintenance dose

### **Important extra information:**

If any symptoms of adrenal insufficiency arise while reducing the stress dose, first go back a step in the table and then allow **2 days for each reduction step**.

### **What should I do if I am ill for a long time?**

Consult your GP if you feel really ill for longer than 48 hours and/or if you have a fever. Your GP can examine you to find out the underlying cause (for example: sinusitis or cystitis). If it is necessary, the GP will give you supplementary treatment. Tell your GP that you have adrenal insufficiency. If necessary, your GP can consult with your endocrinologist.

Do you want further advice about the hydrocortisone stress dose? Then get in touch with your endocrinologist.



### **How can hydrocortisone (Solu-Cortef®) be administered?**

Hydrocortisone (Solu-Cortef®) can be administered by means of an injection into a muscle. You, or someone close to you, can learn how to do this; your endocrinologist or perhaps your GP will help you. Another method is by means of an injection into a blood vessel or via an IV line. Injections into a blood vessel may only be carried out by people who have been trained and authorised to do so.

With certain coagulation disorders, or the use of certain blood thinners (for example: acenocoumarol or phenprocoumon), it is better that you do not have an injection in your muscle, because there is then a greater risk of bleeding in the muscle. If you take blood thinners, you will have to discuss alternatives with your endocrinologist. Quite often it is decided that the GP will administer hydrocortisone (Solu-Cortef®) into a vein. It is also possible for hydrocortisone (Solu-Cortef®) to be administered by means of two injections under the skin.

### **When do I need to contact my endocrinologist?**

In the Guidelines above you can see when you should contact your endocrinologist. You should always contact him:

- if you have persistent vomiting
- if you have persistent watery diarrhoea: once or twice an hour
- if you have reduced awareness or become unconscious.

In addition, you should contact him if you become more and more ill after you have increased the hydrocortisone dose, and you aren't happy about the situation. You should also contact him if you have any doubts about your illness or what you are planning to do.

After an injection with hydrocortisone (Solu-Cortef®) you must always consult your endocrinologist. This is also the case if your GP has given you an injection of hydrocortisone (Solu-Cortef®). Your endocrinologist will determine whether you also need to be examined at A&E and will make any necessary arrangements.

### **How do I prepare myself for possible problems?**

It is very important for you to know precisely when and how you should increase your hydrocortisone intake with tablets and when an emergency injection of hydrocortisone should be administered. Always

carry extra hydrocortisone tablets with you, and take your emergency injection with hydrocortisone (Solu-Cortef®) with you if you are going to be away from home for more than a day. Ask one of your friends or a family member to help you carry out the stress instructions and help you keep an eye on your illness. Discuss the stress instructions with that person and explain what needs to happen if there is a threat of an Addison crisis. Also ask this person if he or she is willing to take a training course to be able to inject hydrocortisone into a muscle. That is something you can learn to do yourself, as well, but sometimes you might be too ill to administer the injection properly.

It is important that you make an appointment with your GP and go through the recommendations in this folder.

Arrange with your GP that he or she will visit you immediately if you need to have an emergency injection and you and/or your injection buddy are not able, or no longer able, to do it. This needs to be noted in your patient records, so that the after-hours medical post is also aware of it.

Wear an SOS medallion and carry a medical declaration (SOS emergency declaration) with you so that in an emergency other healthcare providers will know that you have adrenal insufficiency. Various SOS medallions are available. You can order them from your pharmacy or a jeweller, or order them online from the 'whitecross foundation' or some other webshop on the internet.

Besides an SOS medallion, there are also other ways of letting healthcare providers know - in an emergency situation - that you have adrenal insufficiency. The best options are:

- programme 'In Case of Emergency' (ICE) into your telephone
- a European Emergency Card

### **What do I have to bear in mind when I go on a journey?**

If you are planning a long-distance journey, bear in mind that you have adrenal insufficiency. It is important that you can make use of local medical facilities if you have an Addison crisis or one threatens.

We recommend that you do not travel to locations where medical assistance is not available, or difficult to access. If you have any queries, get in touch with

your endocrinologist or the endocrinology nurse-specialist.

We recommend that you take at least the following items with you if you are travelling abroad or will be away from home for some time:

- sufficient medication, for example 60 mg of hydrocortisone for each day, so that you have enough to fall back on if you become ill or lose some of your medication
- sachets of ORS and possibly loperamide tablets in case you get a severe bout of diarrhoea
- medical declaration or SOS emergency declaration (a summary of your medical condition in Dutch and in English)
- medical passport (can be obtained from your pharmacy)
- the 'Guidelines for taking hydrocortisone to prevent an Addison crisis'
- 1 or 2 vials containing 100 mg of hydrocortisone (Solu-Cortef®), plus a syringe, a drawing-up needle and an injection needle

Dutch citizens can find more information about how to prepare for an international journey on the website of the Dutch Adrenal Society NVACP ([www.nvacp.nl](http://www.nvacp.nl)), the website of the CAK (central administration office for medical expenses, [www.hetcak.nl](http://www.hetcak.nl)) and the government website ([www.rijksoverheid.nl](http://www.rijksoverheid.nl)). Depending on your destination, you can also consult a Travel Clinic.

#### Further information

For further information in Dutch, go to the BijnierNET (AdrenalNET) website ([www.bijniernet.nl](http://www.bijniernet.nl)) and the website of the Dutch Adrenal Society (Bijniervereniging) NVACP ([www.nvacp.nl](http://www.nvacp.nl)). Info in other languages go to [www.adrenals.eu](http://www.adrenals.eu). In case of doubts: consult your local specialist.

#### Use of the folder

The folder 'Increasing your hydrocortisone to prevent an Addison crisis' is a product of BijnierNET. You are free to copy and distribute the folder but you may not make any alterations to the text. If you have any queries, please get in touch with the working group 'Guidelines for taking hydrocortisone to prevent an Addison crisis' via [www.bijniemet.nl](http://www.bijniemet.nl).

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