

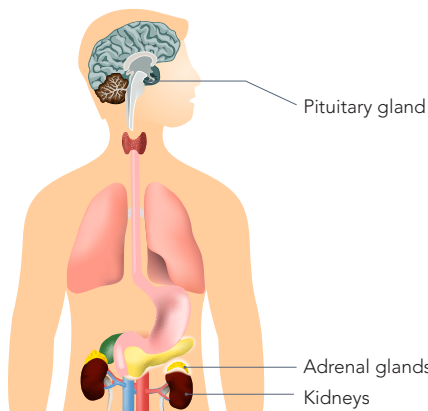
# Adrenal insufficiency: When your body does not make enough cortisol hormone

Health information after cancer treatment as a child or teenager

The purpose of this factsheet is to tell you about long-term side effects (called 'late effects') that can happen after having cancer treatment. They can happen soon after treatment has finished or later in life. The medical team at the hospital where you received your treatment or your long-term follow-up team will be able to help you with specific information about which late effects are relevant to you.

## What is cortisol?

The hormone cortisol is important to make sure that your body can cope with stress, especially when there is an illness or injury. It is made by your adrenal glands which are located above both kidneys.



Cortisol is controlled by the hormones produced by the pituitary gland in your brain (see CCLG pituitary gland factsheets). When your adrenal gland can't produce enough cortisol hormone, we call this **adrenal insufficiency** or **cortisol deficiency**. Other terms that may be used are **ACTH (pituitary hormone) deficiency** and **adrenal failure**.

There are 2 types of adrenal insufficiency:

- **primary adrenal insufficiency** is rare in cancer survivors and happens when the adrenal glands themselves are damaged and are unable to make enough cortisol hormone (other adrenal hormones will also be affected).
- **secondary adrenal insufficiency** (the most common type in cancer survivors) happens when the pituitary gland in the brain is not making enough

adrenocorticotrophic hormone (ACTH), which means the adrenal gland doesn't make enough cortisol and deficiency occurs.

Depending on the cancer treatment you received, cortisol deficiency can happen immediately or, following radiotherapy, it can happen over many years. There is a chance that at some point in your life, you may develop cortisol deficiency, even if you aren't showing signs at this time. If you are at risk of cortisol deficiency, it is important that you have regular checks of your cortisol hormone.

## What do I look out for?

If you have low cortisol levels, you may have no symptoms or only mild symptoms such as feeling tired or exhausted, general weakness, dizziness, or feeling less hungry. However, when faced with physical stress such as an infection, injury or surgery, you may become very ill with low blood pressure, low glucose levels, vomiting, diarrhoea and dehydration.

## Who is at risk?

**Primary adrenal insufficiency** can happen when you have had:

- cancer of the adrenal glands
- chemotherapy that has destroyed the adrenal glands
- surgical removal of the adrenal glands

**Secondary adrenal insufficiency** can happen when you have had:

- tumour/cancer of the brain, hypothalamus or pituitary gland
- surgery to the brain, hypothalamus or pituitary gland

- radiotherapy to the head/brain, eye/eye socket, nose, face, particularly after high doses but also after low doses many years later (more than 10 years), including after stem cell transplantation with total body irradiation, especially anyone who also had a cranial radiation boost.

Some people who have had very high doses of steroid medication (such as dexamethasone, prednisolone or hydrocortisone) during cancer treatment, may have temporary secondary adrenal insufficiency. This is because when high doses of steroids are given, the body thinks that there is less need to make its own cortisol. Therefore, when steroids are stopped, the body hasn't had enough time to re-adjust its own production to match its needs, and becomes temporarily cortisol deficient. While this is usually short term, some supplementation may be needed until complete recovery to keep you well.

## How do we monitor adrenal insufficiency?

Adrenal insufficiency is screened by a blood test. High-risk patients should have an early morning blood cortisol level checked at least once a year if there are symptoms suggestive of cortisol deficiency.

If the early morning cortisol level is unsatisfactory, a blood test called the Synacthen test will be needed. This test involves an injection of a medication into a cannula and one blood sample being taken before and at least one sample after the injection.

## How is adrenal insufficiency treated?

Adrenal insufficiency is treated by oral hydrocortisone tablets usually two, three or sometimes four times a day. When you are unwell, you need to follow standard 'sick day rules':

- if you have a high temperature (38°C) or have started antibiotics, the dose of hydrocortisone needs to be

increased as per your medical team's instructions because that is what your own body would do if it was able to produce its own cortisol.

- if you are being sick or can't take your hydrocortisone tablet for other reasons, you need to have treatment by injection. If your doctor has given you an emergency hydrocortisone injection to have at home, you should inject yourself or get somebody else to, or you will have to go to hospital. If you have the hydrocortisone injection at home, you should seek medical advice.

## What can I do?

You cannot prevent adrenal insufficiency from developing, but you can make sure problems are picked up and treated early by:

- **attending all your check-ups**, so that you can be reviewed and monitored regularly
- **speaking to your doctor** if you are tired/feel unwell

If your tests show you do have adrenal insufficiency, you should take your medication as recommended and keep safe by following 'sick day rules' and making sure you always carry evidence that you are taking hydrocortisone such as MedicAlert jewellery or a steroid card in your purse or wallet, or information on your mobile phone.

## Where can I find more information?

**Addison's Disease Self-Help Group**  
[www.addisons.org.uk](http://www.addisons.org.uk)

**The Pituitary Foundation**  
[www.pituitary.org.uk](http://www.pituitary.org.uk)



the **EXPERTS**  
in **CHILDHOOD**  
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ChildrensCLG CCLG\_UK

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Written by CCLG Late Effects Group, a national network of experts who specialise in looking after young cancer survivors, in conjunction with the CCLG Information Advisory Group, comprising multiprofessional experts in the field of children's cancer. If you have any comments on this factsheet, please contact us. CCLG publications on a variety of topics related to children's cancer are available to order or download free of charge from our website.

Children's Cancer and Leukaemia Group (CCLG) is a leading national charity and expert voice for all childhood cancers.

Each week in the UK and Ireland, more than 30 children are diagnosed with cancer. Our network of dedicated professional members work together in treatment, care and research to help shape a future where all children with cancer survive and live happy, healthy and independent lives.

We fund and support innovative world-class research and collaborate, both nationally and internationally, to drive forward improvements in childhood cancer. Our award-winning information resources help lessen the anxiety, stress and loneliness commonly felt by families, giving support throughout the cancer journey.

Our work is funded by donations. If you would like to help, text 'CCLG' to 70300 to donate £3. You may be charged for one text message at your network's standard or charity rate. CCLG (registered charity numbers 1182637 and SC049948) will receive 100% of your donation.