

Plain Text of ... The LUNA Project From Me and My Friends Resource on:

Adrenal Insufficiency (uh·dree·nuhl in·suh·fi·shuhn·see)

What is adrenal insufficiency?

Adrenal Insufficiency is a condition where the adrenal glands don't produce cortisol, which we all need to survive and cope with everyday stresses. It can affect any age group and has a number of causes which impact the adrenal glands in different ways. These causes can be primary or secondary. One of the best known types of primary adrenal insufficiency is Addison's Disease. This is an autoimmune disease where the adrenal glands are damaged by the immune system. This often impacts both cortisol and another hormone called aldosterone. Secondary adrenal insufficiency (SAI) is often due to long term steroid medication, radiation or injury and so generally only impacts cortisol production. The most common symptoms are fatigue, muscle weakness, dizziness, weight loss, low mood and intense salt cravings. In an adrenal crisis the condition can cause delirium, severe pain, loss of consciousness and if left untreated, death. Adrenal Insufficiency is a life-long condition that is managed by replacement steroids to provide the missing cortisol. This is most often hydrocortisone or prednisolone, on a dosing schedule similar to what you should naturally produce.

How does adrenal insufficiency affect me..

Physically?

Living with adrenal insufficiency can vary from person to person, depending on the cause and how well controlled it is. For many the physical symptoms include fatigue, nausea, dizziness and hyperpigmentation. These symptoms can be difficult to manage until the correct dose of steroids is found, along with the right dosing schedule. This can take time as dosages often need to be divided out over the day following your personal circadian rhythm. This can be found by doing a test or through trial and error. Once the ideal is found, some live completely 'normal' lives on medication, whereas for others one or two symptoms will remain. Fatigue is common and the impact this has cannot be underestimated. It can feel like you have a constant hangover or the flu. It's important to explain this to your loved ones so that they can help you manage.

Mentally?

Being diagnosed with a life-long condition can be a very hard and uncertain time. Add in the life threatening nature of an adrenal crisis and it can be really tough to handle mentally. I am very lucky to have close friends and family who are able to support me, but it's important to know that most people go on to live full and long lives with this condition. After my first crisis it took time and support for me to be able to talk openly about it, and realise my mortality fears. It's so important to find your own way to be able to live safely with this condition, without living in fear.

My life...

My secondary adrenal insufficiency is effectively managed with multiple doses of hydrocortisone everyday to imitate natural cortisol production. It doesn't impact my choice of career, my relationship or my daily life.

The issue comes when I get unwell or stressed. Everyone who is diagnosed has to carry medical ID , a steroid card and an injection kit. You will be trained to inject, often along with whoever you live with. This is due to the risk of crisis.

If I have a stomach bug, an infection, injury or period of high stress I have to increase my steroid dose orally to reflect the natural increase in cortisol my body should create to cope with these situations. These are known as the 'sick day rules'. Following these rules means that in the 3 years since my diagnosis, I've only had one crisis. Some people never have one.

If the rules don't work then I have to inject myself and dial 999. This can be really scary and hopefully it will never happen to you, but if it does then that injection will save your life. The injection works faster to get cortisol levels back to a safe place, until you can receive proper medical attention.

Adrenal Insufficiency Essentials

Image 1:

A colour photograph showing a plastic container with the words 'Emergency Injection Kit' on the top and visible contents of a steroid card, along with some medical packaging. The subtext reads 'Emergency Injection Kit with vials of hydrocortisone, needles and instructions'.

Image 2:

A colour photograph of a wrist with a silver chain bracelet, on a white background. In the middle of the bracelet is an oblong shaped piece of silver with the medical symbol of a snake in red. The subtext reads 'Medical ID with emergency information on the reverse. I wear it 24/7'.

Image 3:

A colour photograph of a box of medication and a sachet of pills crossing diagonally. The box and sachet both read Hydrocortisone 10mg. The subtext reads 'Spare steroid tablets for increasing my dose when needed. I keep them in my handbag, jacket pockets and beside my bed'.

Ways a friend can help

When out and about realise that your friend may need to rest more and to take medication regularly. Especially in the early days, it can be an adjustment and it's important that they know you are there for them. You both need to know that nothing has changed, and your friendship is still the same. Just with a few less all night parties.

It is also really important for close friends and family to learn the warning signs of a crisis. These are often personal but vomiting, losing consciousness, severe pain and not making sense are really common. If you are ever unsure, dial 999 and say 'adrenal crisis'.

If they are unlucky enough to experience a crisis, recovery can be tough, and has been likened to severe jet lag or drug withdrawal. It is so important to know what to do in an emergency, but afterwards to make sure you help to support their recovery both mentally and physically.

If your friend has recently been diagnosed or been through a crisis, it's really important to give them the opportunity to talk about it. Mortality is not a topic many people feel comfortable discussing, but once you start it really does get easier. A crisis or new diagnosis is scary for everyone but being able to openly discuss the ups and downs is so important.

Find out more...

- Addisons Disease UK - <https://www.addisonsdisease.org.uk> -This charity has a wealth of information on the condition, as well as informative videos about injections.
- UK Addison's Disease & AI Info & Support Group - This private facebook group is an invaluable support network with lots of informative links and support for anyone with the condition.
- It's also worth having a look at some of our blogs, podcasts or socials.

About the author

Heather (she/her) is 28 and lives in Scotland. Originally from Aberdeenshire, she now lives in Glasgow. Having previously worked for the Courts Service and gaining a law degree, she is currently taking a career break due to illness / disability.

Get involved!

We would love to get as many people involved in creating these resources as possible!

If you are a young person living with a chronic illness, disability, or long term health

condition, and would be interested in making a similar resource based on YOUR

experiences, we would love to hear from you! You can email us at

thelunaprojectuk@gmail.com ! You can also find us on social media [@thelunaprojectuk](https://www.instagram.com/thelunaprojectuk)

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