



# The Newbie Tool-Kit

## A 10-POINT CHECKLIST FOR THE NEWLY DIAGNOSED PATIENT

### **You have been diagnosed with a form of adrenal insufficiency by your doctor.**

Adrenal insufficiency, including Addison's disease, is a rare endocrine (or hormonal) disorder. It occurs when the adrenal glands cease to produce cortisol and, in some cases, aldosterone and androgens. Cortisol is a steroid hormone which is essential for a wide range of processes throughout the body including metabolism and the immune response. It also plays a very important role in helping the body respond to stress. Failure of the adrenal glands therefore requires lifelong, continuous cortisol replacement therapy.

With constant and correct replacement therapy, most patients will see marked improvement in symptoms. Many will be able to return to a lifestyle similar to what they experienced prior to diagnosis. Despite this, some patients remain with an impaired quality of life, and should discuss options with their physician to optimize quality of life.

However, if a sudden emotional or physical stress (e.g. an accident/trauma or fever/infection) occurs, the disease can quickly progress to a condition called an Addisonian crisis, adrenal crisis or acute adrenal insufficiency. This is a potentially life-threatening situation and requires immediate emergency treatment.

### **Over time, you will learn to listen to your body, adjust your life accordingly and, work in close cooperation with your doctor to best manage your condition.**

Every person living with adrenal insufficiency as well as their family and close friends should know and understand:

#### **1. Continuous, life-long cortisol replacement therapy is essential for life.**

Take your medication as prescribed by your doctor, every day at the correct time. Do not skip a dose. If you do forget a dose, take it as soon as you remember and continue with the rest of your doses. It can be helpful to set alarms on your mobile phone as a reminder with a 5 minute snooze alarm in case you get distracted. Never abruptly stop taking your medication.

#### **2. Inform your doctor if you are not doing well on your medication.**

There is no fixed treatment regimen, each patient is different! Your doctor can help you find the best doses and when/how often to take them. But they won't be able to help you if they are unaware that you are struggling. Medication requirements may also change over time.

#### **3. Always report any changes in your health to your doctor.**

Newly prescribed drugs to treat other conditions may influence the cortisol metabolism and require adjusting of your daily hydrocortisone dose.

If you were diagnosed with primary adrenal insufficiency of autoimmune origin (Addison's disease), you may already have or may develop symptoms and signs of other autoimmune disorders over time.



**4. Learn about stress- and sick day dosing.**

During physical or extreme mental stress as well as during illnesses, injury or surgery, the usual cortisol dose may need to be increased to prevent an adrenal crisis.

The most common stress dosing is required in circumstances such as accident, injury, fever, diarrhoea, vomiting, influenza or extreme emotional stress to prevent an adrenal crisis.

**5. Learn about low cortisol symptoms and the signs of an adrenal crisis.**

Over time, you will become aware of your personal signs of low cortisol and impending crisis. You will also get to know what level of up-dosing is needed in times of stress. Each of us will respond differently to what extra dosing is needed to keep us out of trouble. The guidelines are average recommendations, but as individuals this may differ.

**6. Learn when and how to give yourself an emergency injection\*.**

It is recommended to use your emergency injection kit at the first sign of an adrenal crisis to avoid spiralling into a critical state. If unsure whether or not to inject, it is better to err on the side of caution rather than risk adrenal crisis. One injection won't harm you and may well save your life.

**7. Help medical professionals to recognise your condition quickly.**

Always wear a medical alert bracelet and carry an emergency letter from your doctor explaining your condition and including their contact information.

Always carry an emergency kit consisting of soluble hydrocortisone medication/act-o-vial\*, syringes and needles for injection.

Notify medical staff before undergoing planned or emergency surgical procedures.

**8. Be prepared.**

Always carry spare medication (tablets) and your emergency injection kit.

Order repeat prescriptions in plenty of time – ideally maintaining a 3 months reserve supply – to ensure you do not run out of essential medication.

Take an extra supply of medication (e.g. double what you would normally need) when travelling or on holidays plus the injection kit. Carry your medication / injection kit in your hand luggage when travelling by plane, along with a doctor's note explaining why you need to carry medications, needles and syringes.

**9. Learn how to take care of yourself.**

Ensure that you pace yourself, get the rest your body needs and maintain a healthy diet. Approach exercise within your ability and limitations. In hot weather, it is important to replace fluids and electrolytes adequately.

**10. Be your own advocate.**

Remember: adrenal insufficiency is a rare condition. Not every health care professional has encountered a patient with adrenal insufficiency during his or her career and therefore may not be up-to-date on treatment guidelines and / or protocols.

\*\* Example brands are: Solu-Cortef or Solu-Medrol.

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