

FACT SHEET

10 POINT CHECKLIST FOR THE NEWLY DIAGNOSED PATIENT WITH ADRENAL INSUFFICIENCY

You have been diagnosed with a form of adrenal insufficiency

Adrenal insufficiency, including Addison's disease, is a rare endocrine disorder.

It occurs when the adrenal glands cease to produce cortisol (primary) or the pituitary gland does not signal the adrenal glands to produce cortisol (secondary). In some cases, mainly primary, aldosterone and androgens are not produced. 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.

Under correct and constant replacement therapy, most people living with adrenal insufficiency can live a normal and productive 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 adrenal crisis. 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 phone or watch as a reminder with a 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 affect the absorption of your adrenal insufficiency medication/s. Please check with your doctor or pharmacist.

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

4. Learn about stress dosing 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 circumstances for stress dosing occurs with an accident, injury, fever, diarrhoea, vomiting, influenza or extreme emotional stress. Stress dosing is used to prevent an adrenal crisis.

FACT SHEET



www.addisons.org.au

10 POINT CHECKLIST FOR THE NEWLY DIAGNOSED PATIENT WITH ADRENAL INSUFFICIENCY

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. Each of us will respond differently to the extra dosing needed to keep us out of trouble. Guidelines are average recommendations, but as individuals this may differ.

6. Learn when and how to give yourself an emergency injection of injectable hydrocortisone.

It is recommended to use your injection 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 an 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 bracelet and carry an emergency letter from your doctor explaining your condition, including their contact information.

Always carry an emergency injection kit consisting of injectable hydrocortisone, syringes and needles.

Notify medical staff before undergoing planned or emergency surgical procedures.

8. Be prepared.

Always carry spare medication (tablets) and your emergency injection kit (injectable hydrocortisone, needles and syringes).

Order repeat prescriptions in plenty of time – ideally maintain a 3 month 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.

More detailed information can be found on the AADAI Website at www.addisons.org.au

