



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 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.

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 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 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 stress dosing is required occurs with an accident, injury, fever, diarrhoea, vomiting, influenza or extreme emotional stress. Stress dosing is used 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. Each of us will respond differently to the extra dosing 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 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 and 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 and syringes).

Order repeat prescriptions in plenty of time – ideally maintaining 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



Where to find support and further information about adrenal insufficiency

Australian Addison's Disease Association Inc. (AADAI)

Although Addison's disease and adrenal insufficiency are rare diseases, you are not alone. The Australian Addison's Disease Association Inc. (founded in 1995) is a non-profit organisation with more than 300 members across the country who are living with adrenal insufficiency. It strives to improve outcomes for people with this rare condition by providing up-to-date information and ongoing support.

Drawing on the expertise of leading Australian and overseas experts, the Association maintains the website www.addisons.org.au, staffs a support line (0455 534 472), publishes regular newsletters, and organises seminars, coffee groups and events. It also conducts important advocacy work with government departments and other health and medical stakeholders to improve the diagnosis and treatment of people with adrenal insufficiency.

Membership is open to people living with Addison's disease and adrenal insufficiency and their family and friends.

Membership benefits include:

- A new member kit via mail which includes a range of information, an emergency identity card, an Adrenal Crisis Information letter and Solu-Cortef® cases for your injectable hydrocortisone
- Regular newsletters via email
- Access to the "Members only" section of website
- Invitations and free access to AADAI organised seminars and events

Visit www.addisons.org.au for a wealth of information as well as treatment protocols.

AADAI Annual Seminars and support group meetings throughout Australia

Once a year, the AADAI organises a seminar in Sydney, NSW for people living with Addison's disease and adrenal insufficiency and their families, friends and / or caregivers. Among the speakers are an endocrinologist and other health professionals. Hands-on instructions on how to give hydrocortisone injections are provided.

In addition, AADAI state representatives and coffee group hosts organise local meetings and catchups for members.

Check the Events section of our Website for up-to-date announcements:

www.addisons.org.au/events