You have been diagnosed with **Addison's disease**. Here is some information to help you manage your health

Managing Addison's disease

Addison's Disease Self Help Group – Addison's Clinical Advisory Panel

The Addison's Clinical Advisory Panel is a group of endocrinologists with an interest in adrenal medicine. It advises the Addison's Disease Self-Help Group on medical matters. The ADSHG works to support people with adrenal failure and to promote better medical understanding of this rare condition.
Registered charity 1106791.

www.addisons.org.uk

This leaflet has been prepared by the Addison's Clinical Advisory Panel (ACAP): Professor John Wass of the Churchill Hospital, Oxford, Dr Trevor Howlett of the Leicester Royal Infirmary, Dr Wiebke Arlt of the University Hospital, Birmingham and Dr Simon Pearce of the Royal Victoria Infirmary, Newcastle. ACAP has also issued clinical guidelines for emergency treatment of hypoadrenalism and glucocorticoid medication for surgery and dentistry. These are available from the ADSHG at ***www.addisons.org.uk/publications***

1 WHAT IS ADDISON'S DISEASE?

Addison's disease is a rare endocrine condition where the adrenal glands cease to function, so that your body no longer produces enough of certain essential hormones, known as steroid hormones. Fortunately, you can replace these essential hormones with daily steroid tablets. The hormones that your body no longer produces enough of are:

- **Cortisol, aldosterone and DHEA** *(primary adrenal insufficiency).*
- **Cortisol and DHEA** *(secondary adrenal insufficiency).*

Cortisol regulates blood pressure, blood sugar and muscle strength; aldosterone regulates sodium and fluid balance; DHEA influences stamina and libido.

2 HOW IS ADDISON'S DISEASE DIAGNOSED?

Diagnosis is done by hospital blood tests and an assessment of your physical symptoms. The main blood test measures how much (or how little) cortisol your body can produce. It is called a Synacthen (ACTH stimulation) test. Additional hospital blood tests will measure your aldosterone function. These are plasma renin, sodium & potassium tests.

3 HOW IS ADDISON'S DISEASE TREATED?

Lifelong, daily steroid medication is essential. Most people take their medication three times a day, starting when they first wake up and then at five to six hourly intervals in the day. In the UK, you will probably be prescribed:

- **Hydrocortisone 15mg – 25mg per day**
  This replaces cortisol and is usually taken in three divided doses.
- **Fludrocortisone 50mcg – 200mcg per day**
  This replaces aldosterone and is usually taken in a single morning dose.
- **Possibly, DHEA 25mg – 50mg per day**
  This is usually taken in a single morning dose.

Most specialists will also prescribe an emergency injection kit in case of vomiting:

- **Efcortesol 100mg** (liquid) or
- **Solu-Cortef 100mg** (powder) plus vial of water.

4 WHAT DO I NEED TO KNOW ABOUT MANAGING MY MEDICATION?

- Take your tablets **every day**, at the **right time of day**. They are essential for life.
- You can take your hydrocortisone on an empty stomach, unless you have pre-existing digestive problems.
- Always carry spare medication with you.
- Order your repeat prescription in plenty of time – ideally maintaining a month's reserve supply – to ensure you do not run out of essential medication.
- Take an extra supply of medication **(**ie **double what you need)** with you on holiday plus your injection kit.
- Carry your medication and injection kit in your hand luggage when travelling by plane, along with a doctor's note explaining why you need to carry needles and syringes.
- It can take several months after diagnosis to get the balance of your medication adjusted to the right amount and timing.
- Over time, your medication requirements can change. Mostly in the early years after diagnosis, a small proportion of people with primary Addison's can do without fludrocortisone.
- You will need to work with your doctors to monitor any new symptoms which might mean you need to adjust your medication.

5 ARE THERE ANY SPECIAL PRECAUTIONS I WILL NEED TO TAKE?

You will need to take extra medication whenever you are sick or injured and before any kind of surgery. The general guidelines for extra steroid cover are:

- **Double your normal daily dose for a fever of more than 37.5 C.**
- **Take 20mg hydrocortisone immediately after you vomit and sip rehydration/ electrolyte fluids (Dioralyte).**
- **If you vomit twice and cannot keep medication down, use your emergency injection kit. Then call a doctor.**
- **Take 20mg orally immediately for serious injury to avoid shock.**
- **Ensure your surgical team is aware of your need for extra medication and that they have checked the surgical guidelines for the correct level of steroid cover.**

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6 WHAT COULD GO WRONG IF I DON'T TAKE ENOUGH MEDICATION?

Patients taking the precautions recommended in section 5 usually manage their illnesses smoothly, without going into crisis. But in cases of vomiting or shock, people with Addison's can experience a sudden drop in blood pressure. If you do not take sufficient extra medication, you may experience an **adrenal crisis**.

Adrenal crisis is a state of acute cortisol shortage with similar symptoms to your pre-diagnosis illness. Warning signs include: severe nausea, headache, dizziness, extreme weakness, chills or fever, confusion.

- **If you feel severely unwell, take extra medication then call a doctor.**
- **An emergency injection followed by urgent hospital treatment is needed for an adrenal crisis.**
- We recommend that you wear a MedicAlert bracelet. MedicAlert keep emergency treatment instructions on file and will attach these to your records.
- If your job involves the risk of physical injury (eg fire services, military) you will need to advise your employers of the risks of adrenal crisis and ensure that colleagues are trained to administer an emergency injection if needed.

7 WHAT KIND OF MEDICAL SUPPORT AND MONITORING WILL I NEED?

Usually, your endocrinologist will want to see you as an outpatient every 6-12 months.

- Around half of those with autoimmune Addison's will develop another endocrine condition – like hypothyroidism – at some stage in their life. Your endocrinologist will monitor for this or other conditions such as diabetes.

Your GP will provide regular healthcare, such as support for minor illnesses in between these visits and will issue repeat prescriptions for your medication.

- You need to ensure your GP understands the nature of your condition, your medication dependency and your occasional need for emergency care.

You are entitled to receive your medication free of prescription charges.

- Your GP must certify your entitlement to free precriptions on a Medical Exemption card.

8 WHAT KIND OF QUALITY OF LIFE CAN I EXPECT?

- People with Addison's can expect to have a normal life span. It is not unknown for people with Addison's to live into their 90s.
- There are no restrictions on activities such as driving. It is a good idea to keep a second injection kit in the car, in case of injury.
- There is no need to adopt a special diet or any dietary restrictions, although a low-salt diet is usually best avoided.
- Most people – including those with exceptional fitness – experience episodes of unusual fatigue. At times you will need to allow your body to catch up, with extra rest.

9 CAN I HAVE CHILDREN?

With the right medical support, women can expect to have a healthy pregnancy and normal childbirth. Extra medication is needed for childbirth.

10 WHAT ABOUT SPORT AND EXERCISE?

- Once you have recovered from your pre-diagnosis illness, you can attain a normal level of physical fitness (unless you have other health complications).
- Gentle exercise such as recreational swimming, walking does not usually need extra medication.
- Challenging physical exercise, such as competitive sport, needs extra medication. You may need up to double your normal dose during the competition.
- For any sports with a risk of physical injury, you must ensure that a team-mate has been trained to administer an emergency injection if needed.

11 ARE THERE ANY LONG-TERM SIDE EFFECTS FROM MY MEDICATION?

Most people do not experience any side-effects, because your steroid medication is prescribed at a moderate replacement dose, rather than the high pharmacological doses used to treat conditions like asthma.

- If your dose is too high, so that you are heavily over-medicated, there are long-term risks of osteoporosis, excessive weight gain or Type 2 diabetes.
- A few people have severe reactions to the fillers in standard medication, eg. lactose intolerance, and need to have their tablets specially prepared.

12 WHY IS IT CALLED ADDISON'S DISEASE?

The condition is named after Thomas Addison, the London doctor who first identified the condition around 1850. It affects up to 140 people per million in the UK. Although it is classified as a disease, it is neither infectious, nor easily inherited.

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WHERE CAN I GET FURTHER INFORMATION?

Information and support are available from the Addison's Disease Self-Help Group (ADSHG), a registered charity run by and for people with Addison's.

For a small annual subscription, the group offers: an information manual, emergency card, print newsletter, electronic discussion group, website, seminars and meetings.

Please contact: **Deana Kenward, ADSHG President, 21 George Road, Guildford GU1 4NP.**
Email: **deana@addisons.org.uk**
Website: **www.addisons.org.uk**

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