

4 SOME COMMON CONCERNS

Over the course of a lifetime living with Addison's disease, many people find themselves addressing one or more of the following areas of concern. For simplicity, these have been grouped into three topic areas: experiences common to many Addisonians; experiences associated with low cortisol levels; experiences associated with high cortisol levels.

Please remember that, because most Addisonians take several divided doses of medication a day, it is possible to have experiences associated with both high and low cortisone levels over the course of a day. Don't be alarmed if you do have any of the over or under-medication symptoms mentioned below; with experience you will learn to adjust for them. Talking it through with your doctor, reaching your optimum daily dose and (from time to time) self-medicating as outlined in the sections below, will all minimise the frequency and severity of these symptoms.

a) EXPERIENCES COMMON TO MANY ADDISONIANS

i. Osteoporosis

Osteoporosis is more common among Addisonians than among the population at large.

In this manual, osteoporosis is used as a general term to cover the various types of bone disorder that can be detected by a bone scan (the medical terms used are often *osteopenia*, *osteomalacia* and *osteoporosis*).

Post-menopausal women are most vulnerable, but medical studies of bone density among Addisonians have found some evidence of bone thinning even among younger men. Low levels of DHEA are thought to be partly to blame.

Long-term use of higher doses of steroids is also commonly associated with osteoporosis. By taking the minimum daily dose of hydrocortisone needed, you should not be at increased risk of bone thinning from your steroid medication. But anyone who is consistently over-medicated is increasing the chances of osteoporosis.

Because of these associations, every Addisonian is recommended to take preventative steps to reduce their risks of bone thinning. It is never too early, or too late, to start working on your bone density.

"I have had Addison's for 26 years. I used to be on 40mg hydrocortisone and had done pretty well. Then eleven years ago I was diagnosed with insulin dependent diabetes and found that the insulin was messing up the medication for Addison's, so they switched me to prednisone and fludrocortisone. Now a month ago I had a hypoglycaemic seizure and ended up with several compression fractures in my spine. After the x-ray they also found four old compression fractures which had already healed. At which point they tell me I have osteoporosis and I am 40 years old. The bone loss has wiggled me out because I am a landscape gardener by trade and do a lot of heavy lifting." BRIAN

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ii. What can I do to prevent osteoporosis?

■ You should make sure your diet includes plenty of calcium and vitamin D. The UK climate makes it easy to run low on vitamin D. Supplements containing calcium and vitamin D are available over the counter for those who do not like dairy products, and are also available on prescription from your GP.

■ Exercise helps to build your bone density. This must be weight-bearing exercise (so swimming will have no effect) but walking is excellent. A daily brisk walk of 20 minutes is sufficient, while a gym workout of 30 minutes, three times a week, is even better.

■ Remember that low-calorie diets that encourage the body to burn ketones also cause calcium loss from the bones, and so can advance osteoporosis. A well-balanced diet, as discussed in section 5: Diet, is best.

■ Post-menopausal women are recommended to use hormone replacement therapy as this helps to give protection against osteoporosis.

■ Bone density scans are available. You are recommended to request a bone density scan every five to ten years. Women should make sure they have a bone density scan at the time of menopause, if they have not already had one. You may wish to request a bone density scan soon after diagnosis to establish a baseline for the condition of your bones, although these are not necessarily always readily available in the UK through the NHS.

■ Prescription medications which act to rebuild bone density are available and have been proven to have positive results for those who are already experiencing noticeable levels of bone thinning.

“I take Fosamax daily for my osteoporosis, which is due to prednisone use. I also take calcium with vitamin D. With the help of these, my last bone density study was normal. Previously I had one compression fracture. So Fosamax has worked for me. I just have to keep taking it every day.” SALLY

iii. Weight gain: are steroids to blame?

Before diagnosis, many Addisonians lose a lot of weight. Some of this is because the disease causes them to lose their appetite and they are taking in fewer calories than a healthy person. An important part of this weight loss is also a loss of normal body fluids, as the electrolyte balance becomes destabilised.

Rapid weight gain in the first few weeks of starting medication is usually due to a restoration of the fluid balance. Following this, however, it is easy to put on stored fat. This is partly because most of us are cautious about taking up strenuous exercise after a period of severe illness.

And steroids generally do increase the appetite. The difference in appetite can be subtle so that the weight gain can be slow but sure. In addition, people taking steroid medication can find it harder to mobilise stored fat, so weight once gained is not so easy to lose.

iv. What helps to shed those excess pounds?

If you feel hungry frequently and are eating in quantities such that your weight concerns you, then gradually reducing your daily steroid dose may help you to shed some of this weight.

If you are experiencing symptoms of energy-lag and low blood sugar without necessarily feeling hungry - and you are snacking on food high in sugars and fats to keep you going through the day - then reducing your total daily dose may not be the most helpful way to lose weight. Instead you may need to review the timing of your divided doses so you can maintain your energy levels and cut back on your intake of snack foods.

Like the general population, most Addisonians would find it easier to maintain their ideal body weight if they exercised more regularly.

“I’ve put on 30 pounds with Addison’s. I’ve become aware of how much I was trying to self-medicate with food - I’d nibble on stuff constantly and lately lots of candy in an attempt to get a pick-me-up from the exhaustion I was feeling. It was the only way I knew besides drinking tons of coffee to try to fix feeling tired.” GLENNA

“When I was first diagnosed I was put on too high a dose of prednisone and started gaining weight quickly. Then I changed to 20mg hydrocortisone daily. By being careful to eat minimal carbohydrates I am slowly getting some of the extra off.” CATHY

“I gained well over 10 kilos while I was pregnant and breastfeeding. Then I lost it all again over 12 months as the children got older. I was getting more exercise just pushing the buggy and chasing after them in the playground. I also realised how much dried fruit, chocolate and crisps I had been eating to keep my energy up. I started eating almonds, fresh apples and carrots as my snack foods instead, and broke up my hydrocortisone dose so I was taking smaller amounts more often through the day to keep my energy up. Then I got rid of around one kilo a month.” CATHARYN

b) EXPERIENCES ASSOCIATED WITH LOW CORTISOL LEVELS

v. Why do I feel lousy at certain times of the day?

The most common reason for feeling lousy at certain times in the day is because your cortisol levels are lower than your body needs. Typically this happens when the gap between one divided dose of hydrocortisone and the next is too long. The majority of UK Addisonians who took part in the 1996 survey were taking their hydrocortisone in just two daily doses. More than two-thirds also said they experienced difficulties with low blood sugar at least some of the time.

If you are experiencing any of the symptoms described right, it may mean you need to adjust your hydrocortisone medication so you take it in smaller, more frequent amounts.

■ Low blood sugar (hypoglycaemia) is a common response to low cortisol levels. This usually means feelings of shakiness, wobbliness, irritability, faintness and hunger. Some people simply describe it as ‘brain fog’.

■ Recurrent headaches or joint aches can also be a response to low cortisol levels.

■ Loss of appetite and feelings of mild nausea are a common response to low cortisol levels and will be familiar to many Addisonians from their illness prior to diagnosis.

■ Severe nausea and vertigo are usually more serious indicators of low cortisol levels and are discussed further below.

The point in the day when Addisonians most commonly experience low cortisol levels is mid-afternoon, but some people have similar symptoms when they first wake up.

If you are experiencing symptoms which do not ease once you have taken your next dose of hydrocortisone then you need to raise them with your medical practitioner.

vi. Low blood sugar and the insulin response

Low blood sugar can be accompanied by snack food cravings as the body seeks instant energy sources from high-sugar and high-fat foods. Sadly, a high sugar/carbohydrate/fat loading tends to perpetuate the cycle of energy-lows. This is because these types of snack foods trigger the pancreas to produce large amounts of insulin. The insulin rapidly converts the available blood sugars to stored fat, leaving you with low blood sugar levels again. This process happens more rapidly in overweight people, which can seem particularly unfair.

Some Addisonians swear by a protein-rich snack as the best way to combat low blood sugar or 'brain fog'. Scrambled eggs and nuts are among the pick-me-ups recommended.

vii. Salt and other cravings

■ *Salt cravings are common among Addisonians. We tend to lose salt faster than people with healthy adrenals, so a moderate intake of salty foods is sensible. If you find your desire for salt becomes unusual and you are also experiencing a recurrence of some of your pre-diagnosis symptoms - like dizziness on standing - then you need to raise this with your doctor and have your medication levels checked.*

■ *Cravings for acid tastes such as lemon juice are also common. Some Addisonians have confessed to a liking for pickle juices and other less common acidic flavours.*

■ *Liquorice cravings are unusual and may indicate that your fludrocortisone medication needs increasing. It is important to have this checked with the relevant blood tests before adjusting your fludrocortisone medication.*

■ *Sugar cravings are common in the population at large. However, if you are getting sugar cravings at the same time each day, this may indicate that the timing between your divided doses is too long for you.*

viii. Feeling very thirsty

If you are feeling thirsty all the time and are passing a lot of urine (as many Addisonians experienced prior to diagnosis) this may indicate that your fludrocortisone medication needs increasing. However, these symptoms may also indicate diabetes or a kidney problem, so it is important that you raise them with your doctor and have the relevant blood tests done before adjusting your fludrocortisone medication.

Some people find that occasional symptoms of unusual thirstiness are a useful early warning sign that their hydrocortisone cover is running low and they need to bring the timing of their next dose forward. Large amounts of alcohol, coffee or tea can cause dehydration and Addisonians are especially vulnerable to this.

iv. Dry skin

Dry, cracked skin is a common problem. Low DHEA levels are thought to be partly to blame. Excessively dry skin can also be associated with hypothyroidism, so you may wish to ask for a blood test to check your thyroid function if this is a persistent problem. Most chemists can offer a good range of soothing emollient creams.

“For three years I had a terrible time with headaches. I saw a parade of doctors of various stripes, had CAT scans, MRI scans and all kinds of tests and drugs.

Finally a glucose tolerance test showed that I overproduce insulin in response to a glucose load. As a result, two or three hours after a big carbohydrate meal my glucose level is way too low, I feel terrible and have a mammoth headache. The headaches are due to this hypoglycaemia and the switch in metabolism, which produces ketones. Since eating more protein and less carbohydrate I have no headaches!” DICK

x. Extra pigmentation

Extra pigmentation - an unusual tan or new growth of freckles and moles - is a common feature of Addison's disease prior to diagnosis. For most, this extra pigmentation starts to fade within weeks of beginning medication.

The physiological cause of the pigmentation is high levels of the pituitary hormone ACTH, which stimulates the adrenals. For some individuals who have had long-standing severe Addison's symptoms, the pituitary loses its ability to reset the ACTH levels back down again. In these cases, the extra pigmentation may not fade over time as completely as it would for others.

If you find you are developing new pigmentation while you are taking your normal medication, this could be a sign that your ACTH levels have risen again in response to low blood cortisol. Your doctor may suggest switching to a longer-acting form of medication, or taking your last divided dose later in the evening to damp down your pituitary ACTH levels.

xi. Exhaustion and 'hitting the wall'

Addisonians tend to rely on stored adrenaline to get them through events which are more stressful or physically demanding than usual, to compensate for the fact that our bodies do not produce the boost in cortisol levels that a healthy person could draw on. Then, when the adrenaline rush finishes, we 'hit the wall'. If you are exhausted enough to need bed rest to recover, then a top-up to your normal daily dosage of hydrocortisone is likely to be justified. A little extra, equivalent to one-quarter of your normal daily dose (5mg for someone on 20mg hydrocortisone), may be all that is needed, depending on the severity of your symptoms.

Over time, most Addisonians come to recognise the kinds of stressful and demanding situations that cause them to reach a state of exhaustion. For some people, it may be giving a conference presentation, for others, it may be big family events such as weddings.

If you are one of those people who find that they reach a state of exhaustion on a regular basis, it is worth keeping a record of the events which lead up to this and reviewing it with your doctor. You may need to adjust your daily medication dose, or you may simply need to be aware of the circumstances in which you have to 'top up' your regular medication. Bear in mind that top-ups should be used sparingly, as taking too much steroid makes you more likely to develop osteoporosis.

xii. Nausea and vertigo

These are the two symptoms most commonly reported by Addisonians who are close to exhaustion or who are running very low on cortisol. For many people these symptoms are preceded by a headache, joint aches or other tell-tale signs. If you experience strong feelings of nausea and vertigo, you need to take your next dose of hydrocortisone immediately. You are likely to need a top-up on your normal daily medication of anywhere between one-third to double your normal daily dose, depending on the severity of your symptoms. Do not be afraid to ring your doctor and ask their advice on how long you should increase your hydrocortisone dose. Experience will teach you what additional dose you need. Make sure you let your doctor know of your symptoms.

“I've started to figure out my symptoms when I am running low. First the fatigue gets worse then I am painfully cold, then come the muscle cramps, then nausea, then vomiting. If I take extra medication in the beginning I seem to break the chain of events. Sometimes too I find that when I am extra tired, feel like I am moving through mud and it hurts to move, then I get dizzy. If I take a bunch of salt, in about half an hour I can feel better.” SHELLY

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c) EXPERIENCES ASSOCIATED WITH HIGH CORTISOL LEVELS

xiii. Insomnia and other sleeping difficulties

Difficulty getting to sleep or getting back to sleep after a middle of the night waking is very common in the population at large and is usually associated with anxieties about work or family life. A small number of Addisonians report that they had difficulty sleeping prior to diagnosis but most report that they were sleeping more than usual as part of their fatigue.

After diagnosis you may find it difficult to get to sleep if you take your last divided dose of the day too late in the evening. The recommended time for the last daily dose is around 6pm, or at least four hours before going to bed.

People with Cushing's disease (who suffer from abnormally high cortisol levels through the night) typically report problems in sleeping. If you are repeatedly having sleep difficulties and are confident there is no other cause, it may be a sign that your total daily dose is higher than you need.

xiv. Anger, mood swings and depression

These feelings are very common in the population at large, so need to be interpreted with caution. However, anger, mood swings and depression can be associated with high levels of cortisol and are noted among people with Cushing's disease. If you feel troubled by these feelings, it may be worth reviewing your medication levels with your doctor and trying out a gradual reduction in your hydrocortisone dose.

A number of Addisonians report that their adrenal symptoms were mistakenly attributed to depression prior to diagnosis. However, a small proportion of Addisonians do also experience clinical depression, and report that they have benefited enormously from seeking medical help and taking anti-depressant medication.

xv. Fluid retention

Puffy ankles and other signs of fluid retention can have a wide variety of causes, including kidney problems and *hypothyroidism*. However, for Addisonians, the first thing to check is your medication levels, as both fludrocortisone and hydrocortisone can affect the fluid balance. A common cause of fluid retention is more fludrocortisone than your body needs. As mentioned earlier, it is important to have the relevant blood tests done before adjusting your fludrocortisone medication.

xvi. Easy bruising

In theory, if you are on the correct steroid dose, you should not experience any of the side effects of steroid medication. In practice, some of the minor side-effects are hard to avoid even on modest doses. Easy bruising is one of these. It results from the effects of hydrocortisone on the capillaries, making them more fragile.

xvii. Thinning skin

A slight amount of thinning skin occurs gradually as we age. However, a sudden and noticeable thinning of the skin can be a side-effect of steroid medication. It results from excess levels of hydrocortisone, which cause protein loss from the body. If you are experiencing this at the same time as some of the other symptoms of excess cortisol described below, this may be as a warning sign that you need to review your medication levels with your doctor and gradually reduce your hydrocortisone dose.

xviii. Muscle weakness/wastage

Some Addisonians lose a lot of muscle strength during their illness prior to diagnosis. It takes hard work and determination to regain this once your medication regime is stabilised, but the experience of other Addisonians shows that it can be done. Also, it is worth remembering that a slight loss of muscle strength occurs gradually as we age.

However, muscle weakness can be one of the few signs of a potassium imbalance and may suggest that your renin and electrolyte levels need to be checked by your doctor.

Prominent muscle wastage can be a sign that you are over-medicated and your hydrocortisone levels are too high. People with Cushing's disease typically experience a thinning of their upper arms and thighs and a sense of muscle weakness. If you are experiencing this at the same time as some of the other symptoms of excess cortisol, you should probably treat this as a warning sign that you need to review your medication levels with your doctor and gradually reduce your hydrocortisone dose.

xix. Puffy/moon face

This can have a wide variety of causes, including hypothyroidism. However, it is also typically found among people with Cushing's disease. If you are experiencing this at the same time as some of the other symptoms of excess cortisol described above, you should probably treat this as a warning sign that you need to review your medication levels with your doctor and gradually reduce your hydrocortisone dose.