

FREQUENTLY ASKED QUESTIONS FOR ADDISON PATIENTS

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ADDISONIAN CRISIS / EMERGENCY

How do you know when to call an ambulance?

If you are careful, you should not have to call an ambulance. If someone with adrenal insufficiency has gastrointestinal problems and is unable to keep down their cortisol or other glucocorticoid for more than 24 hrs, they should be taken to an emergency department so they can be given intravenous solucortef and saline. It is not appropriate to wait until they are so ill that they cannot be taken to the hospital by a family member. If the individual is unable to retain anything by mouth and is very ill, or if they have had a sudden stress such as a fall or an infection, then it would be necessary for them to go by ambulance as soon as possible.

It is important that you should have an emergency kit at home and that someone in the household knows how to use it. The components of the kit must be obtained by prescription from your doctor. If he/she is unfamiliar with the contents of the kit, he/she can look it up on the Canadian Addison Society website (<http://www.addisonsociety.ca/emergencyproc.html>). Your doctor can show you and a family member how to use it, or he/she can print off the instructions from the website for you (<http://www.addisonsociety.ca/injection.html>). There are also instructions in the Solucortef package. The important thing is to have someone in the household who knows how to use it.

The contents of this syringe provide 100mg of cortisol. This will begin acting fairly quickly and will support the individual during the trip to the hospital. This treatment may improve the condition of the individual enough that they will be able to retain fluids and their cortisol so that they will not have to go to hospital. This may be important if you are travelling or are located several hours away from the nearest hospital.

Do you recommend that your patients carry steroids in an injectible form in case of an emergency?

As you know, there is no ideal portable injectible steroid. The most satisfactory preparation is Solu-cortef which comes in a bottle with dry powder and the solvent which can be easily mixed and then drawn up in a syringe for intramuscular or intravenous injection. This combination of 100mg of Solu-cortef and a syringe (10 cc) and needle would be handy if someone were traveling to an out-of-the-way spot. Most emergency departments would have this and they would also give about 1 liter of saline with it.

What is an Addisonian crisis?

Adrenal crisis is caused by shock – a degree of shock which is out of proportion to the illness/trauma. Most Addisonian deaths occur either before diagnosis or in puberty (as some young Addisonians can rebel and experiment). It is possible to have an Addisonian crisis happen once per year. More often might suggest something else is going on - such as hyperthyroid problems, etc. Possibly the steroid dose should be re-evaluated.

When should I use an emergency injection?

In an emergency situation, use hydrocortisone 50-100 mg, and get to a physician (emergency room) as quickly as possible. A 100mg cortisone injection will buy you about 8 hours. If stuck in a long wait at emergency and suffering vomiting and/or diarrhea, you may choose to inject yourself to buy that time.

Although Solu-cortef is the usual emergency medication, it is possible to use dexamethasone 4 mg (no mixing, the but dosage must be more precise) or solu-medrol, which is prednisone.

125mg solu-medrol equates to 700mg – 1000mg cortef. Cortisone suppositories are also a possibility instead of an injection in an emergency.

It is highly recommended that every Addisonian have an emergency kit with solu-cortef on you for emergency situations. The Addisonian has the responsibility to carry emergency medication, which could then be used on airplanes, in trains, in restaurants, or wherever the crisis occurs. For more information on emergency kits, please see our website at <http://www.addisonsociety.ca> - Emergency Procedures and Injection Kit.)

I have a question about the emergency kits that people were talking about. Are they prefilled syringes like the Anakit or is it a multidose vial and a syringe? What is the name of the medication used? Is there a patent name for the Kit? I see an internist not an endocrinologist, and neither my doctor nor pharmacist knows what I am talking about. Do you know of a website or other place where I can find out when to use it?

Sorry if there is some confusion about the injection kit. There is some information on our website about its use (<http://www.addisonsociety.ca/injection.html>, <http://www.addisonsociety.ca/emergencyproc.html>). The kit has to be put together from its components and is not sold as a kit. It consists of:

- Solu-cortef 100mg (or 250mg) Act-o-vial
- 3ml syringe with a 20 or 22 gauge needle
- alcohol wipes

The instructions for mixing the solu-cortef in the vial should be included in the package. You have to ask your doctor for a prescription for these items and you can package them together so the components will not be hard to find.

The reason this does not come already prepared is that the solu-cortef is not stable in solution after mixing.

You should let your travelling companions know that you have this kit with you and they should be shown how to use it if needed. The kit is not much help if no one knows how or when to use it. If you are staying away for a prolonged period, you may want to take more than one kit with you depending on the destination.

You should also have a letter with you from your doctor that says that you have Addison's disease and that you are carrying this kit with you for emergency purposes, so that you don't have any problems at customs.

It will not be surprising if your doctor is not aware of this kit. It is only in the last few years that it has been discussed and she/he may not have any other patients with Addison's disease. If you have any problems, you can copy some relevant information from the web site and take it to her/him or you can direct her/him to the web site.

I read with interest the recommendation of travelling with an injection kit of solu-cortef for emergencies. My endocrinologist has prescribed a pre-loaded syringe of dexamethasone (4.0mg). Do you think this is an acceptable amount to deal with an emergency? It seems to be a simpler way to do it.

A preloaded syringe with 4 mg dexamethasone is a reasonable emergency kit for use when travelling. The main argument against dexamethasone as compared to hydrocortisone is the fact that dexamethasone has very little salt retaining activity - about 1/100 that of hydrocortisone and during acute situations salt retention is important. This is particularly true if you have a fever because you tend to excrete a lot of salt when you have a fever. There is a second thing

you should check and that is the expiry date. The expiry date may be shorter for solutions than for the dry powder in the hydrocortisone Acto- vials. I think the salt retention is the most important consideration.

I have just been confirmed with Addison's Disease. Several internet sites mention that the Addisonian has the responsibility to carry an emergency kit. I have put together every item recommended except for the 100 mg cortisone injection. I cannot find a local pharmacy that supplies this drug. Do I need this item in the kit? If yes, where is it available?

The emergency kit is definitely a worthwhile investment. The solucortef comes in a preparation called the Acto-vial. It requires a prescription from your family doctor or preferably the endocrinologist who made your diagnosis. It is the most important component of your kit. The drug store may not have it in stock but can easily get it for you. You should not have to get all of your information from the net. You should be able to sit down with your endocrinologist and go over these and any other concerns.

What is the treatment when in Addisonian crisis?

Treatment: In adrenal crisis, an intravenous or intramuscular injection of hydrocortisone (an injectable corticosteroid) must be given immediately. Supportive treatment of low blood pressure with intravenous fluids is usually necessary. Hospitalization (at least in the ER) is required for adequate treatment and monitoring. If infection is the cause of the crisis, antibiotic therapy may be needed.

I had an Addisonian crisis last year and almost died, so when I was referred to an endocrinologist, I asked about at home injection kits and if I needed one, as I had read about them; he said I didn't need one. Can I please have your opinion on this? It scares me to know that what I have is rare and I would like to be prepared.

Your endocrinologist probably feels that if you are in a crisis situation, you are better off going to the hospital where you can get both intravenous saline and hydrocortisone and be investigated for the cause of the problem. The emergency kits are important if you are travelling or if you live a distance from the hospital so that in a situation such as a snowstorm, you may be delayed for a significant length of time. I think all individuals with adrenal insufficiency should have an emergency kit at home. They are relatively inexpensive and they give you a feeling of security. If your doctor is unfamiliar with the kit, you can refer her/him the Addison's web site where there is a detailed description. These kits are relatively new but are now being used in many countries.

We just survived our first Addisonian crisis at home. Is it common for an emergency injection (we used solu-cortef, my wife normally takes about 5mg prednisone) to disrupt the menstrual cycle?

Any significant stress can interfere with the regularity of the menstrual cycle. Since there are possibly many factors involved, including why the crisis took place, you should review this with your family doctor or endocrinologist who would know your wife's complete history and would be in a position to access the circumstances.

I was recently diagnosed with Addison's disease and was told I needed to get a Medic-alert bracelet, however I am unsure of what I need to get engraved on it

I am glad to hear that you are getting a medic-alert bracelet. It should say: Addison's Disease on cortisol 20 mg & Florinef 0.1 mg (this is just an example, you can fill in the proper medications and doses).

The important thing is to make sure who ever sees this will know you are on medication and that you need attention, and that the doctors in the emergency room know you are on cortisol or other glucocorticoid and may need solucortef. Paramedics often check on the fridge for medical information. In addition, you can carry in your wallet a note from your doctor stating your diagnosis and any other particulars and medications, and that in an emergency you require intravenous saline and solucortef. (Ed note: examples of such letters can be found on the Society website at <http://www.addisonsociety.ca/emergencylett.html>)

All the literature I have seen specifies administration of hydrocortisone or cortef, in the event of an emergency. If a patient were to experience a sudden drop in blood pressure during surgery (given that pre-stress cortisone had been administered), is it just as effective to administer epinephrine, i.e. norepinephrine instead of hydrocortisone or cortef? Must the ER panic wagon stock both hormones?

Hydrocortisone (cortef) is normally given in an emergency situation because the adrenal releases hydrocortisone in response to the stress of an emergency, whether it is physical or emotional. The amount of hydrocortisone released is proportional to the stress. In a surgical situation, a patient is usually given 100mg of solucortef intravenously prior to the anaesthetic and an additional 100mg each hour during surgery. If the patient had a sudden drop in blood pressure during the operation, I would first give an additional 100mg solucortef at that time, but I would look for other causes of the fall in pressure such as blood loss, lack of an adequate oxygen supply or infection.

Norepinephrine is used to raise blood pressure, but if the problem is a lack of hydrocortisone, it will not be effective. It cannot substitute for hydrocortisone. A crash cart should have both solucortef and norepinephrine. In the emergency department, they would always stock solucortef, epinephrine and norepinephrine. For a patient with adrenal insufficiency, they would administer the solucortef first and if there were other factors causing the fall in blood pressure, they might add norepinephrine.

ADDISONS AND OTHER DISORDERS

I have had Addison's Disease and low thyroid for 23 years. One of my nieces has been diagnosed with celiac. Now a grandniece is still undiagnosed with abdominal problems. There has been some writing in our newsletters regarding a possible relation (for lack of a better expression) between Addison's and celiac. Please refresh my memory.

Celiac disease is an autoimmune disorder induced by gluten intake in individuals who are genetically predisposed to autoimmune disorders. Addison's disease, hypothyroidism and type 1 diabetes are other examples of autoimmune disorders and, statistically, an individual with one autoimmune problem is more likely to have a second autoimmune problem than other individuals in the general population. For example, the association between Addison's disease and Hashimoto's thyroiditis is quite strong, with up to 50% of Addison's patients have in both disorders. The relationship between Addison's disease and celiac disease is not as strong, but is about 100x more likely to occur than in the general population. If you want research information on the subject, you can go to the "Google scholar" web site and type in "celiac disease and Addison's" and you will find articles that may be of interest, although they will usually be rather technical.

The symptoms associated with lupus are very similar to those of Addison's. Is there any connection between Addison's and lupus?

Addison's disease and lupus are both autoimmune diseases, but they rarely occur in the same person. The target for the antibodies in Addison's disease and the cluster of autoimmune disorders that tend to occur with it in some cases is one of the enzymes involved in formation of the hormone secreted by that gland. The target for the antibodies in lupus and related disorders is connective tissue.

I have Addison's and have been on Cortef for about 5 years (10 mg in mornings and 7.5 mgs evenings). Many Addisonians also have diabetes. I understand that these are both endocrine disorders, but does one necessarily indicate the other at some point? This concerns me since I have strong cravings for sugar, as well as salt.

Your question regarding the relationship between Addison's disease and diabetes raises some interesting issues. First of all, there are two types of diabetes. Type 1 diabetes was previously called juvenile diabetes and this is an autoimmune disorder in which antibodies destroy the cells in the pancreas which normally secrete insulin. Individuals with this type of diabetes require insulin. It tends to come on at a younger age, frequently in children.

Type 2 diabetes was previously called adult onset diabetes and it most commonly comes on in adults who are usually overweight. The diabetes occurs because their insulin-producing cells cannot keep up with the increased demand for insulin. Initially, these individuals can be treated with pills that either stimulate the pancreas to release more insulin, or help their insulin to be more effective. Later on, the ability of the insulin-producing cells to make insulin decreases and these individuals may require insulin treatment. Ninety percent of diabetics have type 2 diabetes. This is not an autoimmune disorder.

Addison's disease is primarily an autoimmune disease in North America but there are other causes such as tuberculosis and other infections in areas where these diseases are more common.

Autoimmune Addison's disease can occur by itself, or in association with other autoimmune diseases such as thyroid disease or type 1 diabetes. If it occurs by itself, the individual would have roughly the same chance of developing diabetes as someone in the general population – that is 6 to 9% depending on where you live, weight, lifestyle etc.

If Addison's disease occurs in an adult in association with other autoimmune diseases, the probability of developing type 1 diabetes is roughly 25% and the probability of developing thyroid disease is roughly 50%. (This is known as polyglandular autoimmune syndrome type 2).

Since you cannot change your genetic makeup, the best advice is to keep an active healthy lifestyle. Too much sugar is never good for you. Too much salt is generally not good either, but in someone with Addison's disease, you should have your doctor check your renin and sodium level to be sure your Florinef dose is satisfactory.

I have been diagnosed with Raynaud's Syndrome, and he also sent me to have a test for Sjogren's Syndrome. I also have hypothyroidism, chronic ear pain, and recurring skin infections, and no one has ever gone out on a limb to say whether or not all of these things are related to the Addison's, so I asked. With no hesitation, he said "Yes". Do other Addison's patients have a similar laundry list of odd health problems? Has anyone, is anyone, or will anyone research whether these are related?

Thanks for your question re Sjogren's syndrome, Raynaud's phenomenon, hypothyroidism, adrenal insufficiency (Addison's disease), ear pain and skin infections. The first two disorders are diseases of connective tissue and are felt to be due to the formation of antibodies directed against your own tissue (autoimmune). The next two diseases are also autoimmune and the

antibodies are directed against enzymes involved in the formation of the hormones produced by these glands. Since these two types of problems are autoimmune, they can occur in the same individual, but it is more common for the antibodies to be directed at other organs in the same group. This frequently occurs with the thyroid, adrenal, ovary, pancreas or intestine (celiac disease) in different combinations. The skin infections could be a sign of diabetes, but I am not sure where the ear pain fits in.

I have been told by my family physician that because I take replacement cortisone, I am much more susceptible to fungal infections and that this is one thing that we as Addisonians must be very careful of.

People taking cortisone or prednisone for reasons other than Addison's Disease are usually on high doses. This can cause high blood sugars in some individuals and this will predispose them to fungus infections. Individuals on physiological doses should not be more susceptible. There is a childhood form of autoimmune endocrine disease that is associated with "systemic candidiasis". This is a fungus infection that can involve the gastrointestinal tract. This does not occur in adult onset Addison's disease.

What is the relationship between glaucoma and cortisone treatment?

Glaucoma is a process in which there is an increased pressure inside of the eye and the chances of this increase with age. Patients who are taking normal amounts of cortisone for replacement therapy, such as patients with Addison's disease should not have an increased incidence of glaucoma although they would have the same incidence as is found in the general population.

My daughter has primary Addison's, and is now being investigated for POTS (Postural Orthostatic Tachycardia Syndrome). Her cardiologist is going to do a tilt table test. He has admitted that he is not familiar with Addison's, so I am concerned that if my daughter should pass out during the test, it could bring on a crisis. There is also a possibility that they may give her blood pressure lowering medication during the test - I am wondering how this will affect the Addison's.

Also, in these kinds of situations, how would one go about getting two specialists (the cardiologist and the endocrinologist) to confer with each other, as I am sure that would help to alleviate the uncertainty of having procedures done by doctors who have little knowledge of Addison's.

One of the symptoms of Addison's disease is postural hypotension if they are not adequately replaced with Florinef to give adequate salt retention. The cardiologist should be aware that your daughter has Addison's disease and the medication she is on. In an individual with Addison's disease who is on treatment, the tilt table test would not precipitate a crisis. It is unlikely that they would give her any blood pressure lowering medication.

I am actually surprised that someone with Addison's disease would be investigated for POTS unless she had been perfectly well for a prolonged period and then developed these symptoms rather suddenly. My first approach would be to make sure her adrenal meds were optimized.

If somebody with Addison's disease tests positive for TB with the skin test but the chest x-rays are clear. What does he recommend? Regular x-rays? Treatment with TB antibiotics? Watch for symptoms and follow-up then?

The problem of a positive TB skin test in a patient with Addison's disease is interesting. If this patient is an adult, we may assume that the Addison's disease was caused by tuberculosis

involving the adrenal glands. This is not necessarily true since someone with Addison's disease can get TB just like anyone else. The fact that this person's chest x-ray is negative suggests that they were exposed to the tubercle bacillus but overcame the infection without developing a chest lesion. Another possibility is that they were immunized with B.C.G., which gives a positive skin test but no infection. If the Addison's disease is due to the TB, they must have had the infection for quite a while. We will often give anti TB drugs to new Addisonian patients when we start cortisone (or prednisone) if they have a chest lesion since the cortisone can allow reactivation of the disease. With a clear chest x-ray I would follow with regular chest x-rays. If someone has had a negative skin test and is positive on a follow up skin test; it suggests recent exposure and advice should be sought regarding a course of treatment.

ADDISONS AND OTHER MEDICATIONS

Please comment on the use by an Addisonian of an epi-pen for allergic reactions. Is there an increased reaction if taking a stress dose of cortef?

Individuals with Addison's disease can and should use the epi-pen just like everyone else. It is used for an acute allergic situation and it does not interfere with normal or even excess cortisol replacement.

I was diagnosed with Addison's disease in 1992. I have always been told that I shouldn't take anti-inflammatory medication; can you tell me why? I am currently suffering from muscle spasms. I have been prescribed Baclofen vs. an anti-inflammatory.

Anti inflammatory medications can cause stomach irritation and ulcers. These are the major side effects of non steroidal anti inflammatory drugs. People who are taking steroids such as prednisone for the treatment diseases such as arthritis, are more susceptible to these side effects. In Addison's disease the dose of glucocorticoid is physiological (within the normal range) rather than pharmacological (exceeds the normal range for treatment purposes) so the increased probability of stomach problems is quite low. In a situation where anti inflammatory medications are indicated it is important to be aware of possible side effects but I would not hesitate to use nonsteroidals. It is important to be sure that the drug is being used for the proper indications. This family of drugs is very helpful to treat inflammation, but is not likely to do much for cramping or spasms.

My husband has Addison's. Recently, a doctor was going to give my husband TYLENOL 3 with codeine. We looked up uses and side effects on this product and found, both as a senior and an Addisonian, that this could affect his medical condition. What can it do?

It always poses a dilemma when you read that a drug should be used with caution in individuals with a specific disease. I have seen similar comments regarding Addison's disease but have been unable to find any evidence of a problem related to acetaminophen or codeine use in Addison's disease. If he needs something to control pain, what he is taking is probably one of the better choices. I would carry on cautiously.

What is the difference between Prozac and Zoloft and which is better for Addisonians?

Prozac and Zoloft are similar but are not identical drugs. They both block the re-uptake of serotonin in the brain. I am not aware of any data proving one is better than the other in Addison's patients. Theoretically there should not be a difference.

I was recently diagnosed with Addison's and take 20mg Cortef daily, and also take 150mg Synthroid for hypothyroidism. Can one take prescription Lortab with Cortef?

Lortab is a trade name for hydrocodone, a drug related to codeine. It's used to treat severe pain problems and is generally used for short periods of time because it can be addictive. It can cause dizziness and individuals with Addison's disease may be more susceptible to this, but I am not aware of any specific contraindications. Your pharmacist should be able to give you a printout for hydrocodone including the side effects and contraindications. It is not a drug that I would normally recommend, but your family doctor may have a specific reason to suggest it in your case.

Can you explain the role of DHEA in our system and how the lack of DHEA can affect those with Addison's disease?

The science of hormone replacement and regulation is still very basic.

We know the role of DHEA in the fetus and at puberty, its role in adults is not clear. In a fetus, the adrenal glands are larger than the kidneys. The fetus pumps out large amounts of DHEA in utero, which cross the placenta and is converted to estrogen in the mother, which is necessary to support the pregnancy. Indeed, the majority of the rise in estrogen in pregnant women comes from the fetus. DHEA levels in humans are then very low until puberty, when levels increase and cause the growth of pubic hair. In young adults, DHEA levels are high; indeed, it is created in greater amounts than cortisol or aldosterone. Levels in adults diminish over time, as do the levels of many hormones. Males have sufficient androgens as they make testosterone, and thus seem to need less DHEA. Females need DHEA to provide the necessary androgens. A sign of insufficient adrenal function in women is often a thinning of pubic hair.

DHEA seems to play a role in quality of life, libido, and mood. However, the results of studies are still unclear, and we do not routinely recommend the use of DHEA. We may recommend DHEA if both gluco- and mineralocorticoids are optimized, yet quality of life, libido or mood is still an issue, starting at 25 mg a day up to a maximum of 50 mg a day. Currently, the DHEA on the market is not pharmaceutical grade, and, as it is not regulated, there is no quality control.

DHEA in men increases estradiol levels; in women, it increases testosterone levels. DHEA may be implicated in breast cancer in women. As well, if someone takes DHEA and tries to mimic the levels of a 20-year old woman, what is the impact on a 60-year old woman? This would not mimic the levels of nature.

50 mg DHEA will bring a person's levels to those of a normal 20-30 year old. DHEA levels naturally decrease from the age of 30; at age 60, the levels are approximately 25%.

What is the value of taking Pregnenolone? How does it compare to DHEA? Apparently it is not a restricted drug in Canada. Is this true? What is the connection with cholesterol?

The adrenal cholesterol is converted to pregnenolone and the pregnenolone is converted to DHEA. The machinery required to convert pregnenolone to DHEA is primarily located in the adrenal, the ovaries and testes and possibly in the brain. Pregnenolone is popular because it is not restricted and because it is a steroid but as far as I am aware it has no biological effects.

I'm on a new treatment with Andriol (testosterone pill), which is supposed to raise my DHEA level. I started with three 40mg pills a day, but cut down to two because my mind was racing at night. Can I expect some long-term side effect from this medicine, or would I be better off taking DHEA pills instead. The Andriol does seem to help me heal more quickly

The question regarding testosterone is less clear. Whether or not testosterone will help depends on what your basal testosterone level is. One thing that is clear, is that testosterone will not increase DHEA levels. In studies in which DHEA has been given to women, it will increase testosterone levels but DHEA in the usual doses does not have a significant effect on testosterone in men. Testosterone given to men who are truly testosterone deficient will improve protein and muscle development. Since it is so important to know what your hormone levels are before taking additional hormones, you should have some testing done by your endocrinologist.

I was wondering if you have any history of treating Addison's patients with DHEA therapy in addition to their corticosteroid treatment. My doctor is thinking of supplementing my DHEA for symptoms such hair loss and low libido, but the research I've done is mixed and in many cases controversial. Do you have any insight? I had my doctor test my DHEA levels and they came back as <0.1, so I basically don't have any. I have decided to give it a trial run but was wondering if you know if the supplementation of DHEA interferes with the effectiveness of birth control pills or with hydrocortisone.

You are confused about DHEA use in Addison's patients with good reason. The information in the medical literature is contradictory. There are articles that suggest that it is helpful with certain problems, but none of the articles have shown that it is of general benefit.

The article by Arlt from Germany reported some improvement in sexual interest and others have reported an improvement in attitude, but others have not confirmed these observations. Our study, which went on over two years using 50mg DHEA, did not show a statistical improvement in any of the areas measured but some individuals felt that they were better on the medication.

There are some side effects from DHEA. The most common are acne and hirsutism but there do not seem to be any more serious side effects. I would not discourage you from trying it as long as your expectations are appropriate. It is not generally available but some pharmacies/health stores seem to have it.

Your DHEA level should be undetectable if you have Addison's disease because DHEA is made in the adrenal. Males have low levels of DHEA, probably of testicular origin. Taking DHEA should not interfere with either your cortisol or birth control pill.

DHEA may be useful to some Addisonians, especially those with secondary Addisons (i.e. pituitary failure). The best advice is to try it to see (25 –50mg/day for a 6 month trial). DHEA is the precursor to a host of hormones. However, if the adrenal glands are needed to transform the DHEA, and the adrenal glands are no longer functioning, it will be useless to take DHEA supplements.

ADRENALINE

Whenever I try to explain to my friends and family that I have a disease in which my adrenal glands don't work (i.e. I don't produce adrenaline, among other things), I always get the reaction of "So you don't get scared or excited?". I never know how to respond! There must be a correlation between being scared and having little adrenaline. What is it and what is a better way of explaining it?

This is an interesting question. You are correct that the adrenal makes adrenalin in its inner portion (medulla) and cortisol is made in the outer portion (cortex). Adrenalin and a related hormone, noradrenalin involved in the "fright, flight" response to acute stress, are also produced at the ends of specific nerves. In Addison's disease, the cortex is destroyed by antibodies directed at one of the proteins used in the formation of cortisol. The medulla is left alone so can

still produce adrenalin. Even if the adrenals are removed surgically, the nerve endings produce enough adrenalin and noradrenalin to look after blood pressure needs and our fright response.

Do people with Addison's Disease have adrenaline rushes? Can they have them at all?

Most people with Addison's disease have their adrenals affected by antibodies directed against specific proteins in the adrenal cortex. Adrenaline comes from the central part of the adrenal gland called the medulla. This is left intact by the antibodies so adrenaline can still be produced when required. Much of the adrenaline type of compounds are released from nerve endings, so even individuals who have had their adrenals removed surgically can have a normal response to stressful stimuli.

I'm not so sure about an "adrenaline rush". This is not a medical term but I assume that you are referring to a sudden feeling of excitement that might occur in response to some sudden event. These feelings should still be possible.

What is the impact of Addison's on adrenaline?

If the cortex of the adrenals is not producing cortisol, then the medulla produces less adrenaline. The adrenal medulla needs cortisol locally produced to convert noradrenaline to adrenaline. While most of the adrenaline in the system is derived from nerve synapses (nerve endings) from noradrenaline, Addisonians are low on the form of adrenaline produced in the medulla. And this contributes to Addisonians' inability to respond to stress.

BLOOD PRESSURE

Can low aldosterone present with high blood pressure? A friend was started on 30mg in hospital and increased by the endocrinologist to 40mg. She is extremely thirsty and has gained 20lbs over several weeks. Her blood pressure is high and unstable. The doctor says Florinef is not indicated because her blood pressure is already high.

Low aldosterone will not cause high blood pressure. The decision not to start on Florinef was a reasonable one in someone who has high blood pressure. I suspect the reason your friend gained 20lbs is likely because he/she is on too much cortisol. A dose of 20mg a day of cortisol is usually enough if it is spread throughout the day. While some people feel better on 30mg, I think that 40mg is too much cortisol.

I am an 85 year old male, in excellent health, who has had Addison's disease for 38 years. I have been on the same dosage of Cortisone Acetate since 1968. I take 25mg in the am and 12.5mg in the pm. I started on Florinef in 1978, which I took for about 22 years until my blood pressure started to increase, and the Florinef was discontinued. My systolic reading is from 150 to 175, while my diastolic is 55 to 75. Both are tending to increase. I am now taking 2.5mg of Altace daily. My doctor keeps wanting to increase the Altace because of the high systolic reading. Should I be concerned that my systolic reading is higher than normal, while the diastolic reading is below normal?

The problem of treating high blood pressure in patients with Addison's disease poses some specific problems. Cutting back or stopping the Florinef is logically the first step as has been done in your case. It is important to follow serum potassium once the Florinef has been stopped. The addition of Altace as a next step is a reasonable one, but if this is not achieving the desired result, I tend to try a calcium channel blocker such as verapamil. I would avoid Norvasc because it causes ankle swelling. Your family doctor has obviously taken good care of you and it is reasonable to try to keep your blood pressure under control. At age 85, you may be sensitive to

medication, so it is wise to start at a low dose and gradually increase it if necessary. It is also wise to stop medication that is not achieving the desired result when starting something new to avoid getting on a variety of preparations that cause some cross reactions.

A question was raised about the relationship of high blood pressure and small hemorrhages appearing over the white part of the eyes.

First of all, we try to regulate the amount of Florinef to avoid causing high blood pressure but patients with adrenal problems can have the usual types of high blood pressure seen in the general population. In general, high blood pressure is less common in patients with adrenal insufficiency than in the general population. The small hemorrhages are possibly related to increased fragility of the blood vessels and this can be seen in patients who are taking a little more cortisone or prednisone than they might need. This problem can also result in increased bruising, usually on the legs or areas that receive minor trauma.

My wife has been taking Florinef for 3 months and has suddenly begun to experience serious side effects (dizziness, intense trembling, breathlessness, high BP, confusion, nausea). We know Florinef is the cause as all the symptoms disappeared when she discontinued it. Other than reducing the dose, are there any ways to reduce serious side effects from Florinef? What do Addisonians do who cannot tolerate or are allergic to Florinef?

I doubt if your wife is actually allergic to Florinef or even sensitive to it. The symptoms you described suggest that she was getting too much Florinef, causing excessive salt retention which in turn caused the symptoms. The dose of Florinef must be regulated and varies from individual to individual. Occasionally, individuals can get along without Florinef because they have high blood pressure from other causes. Others need higher doses to regulate their blood pressure. The most sensitive tests to determine the requirement for Florinef are a plasma renin and electrolytes. Your family doctor or endocrinologist will know.

I have Addison's disease, celiac disease, vitiligo, Hashimoto's thyroiditis, early menopause, Type II Diabetes, hypertension and LDL of 120. For years I was on 50mg. hydrocortisone. More recently (10 years) I have been on 15mg Cortef daily. I also take 0.1mg fludrocortisone, 16mg Atacand, 0.125mg Levoxyl and 81mg Aspirin every other day. My doctor also wants me to take 1/2 tablet 10/40 Vytorin. Would less fludrocortisone help lower hypertension without the use of antihypertensives? My blood pressure still runs in the 140/80's even on Atacand.

You have almost the complete spectrum of autoimmune endocrine problems, but it sounds as if you are doing well and are being well looked after. Your doctor wants you to start the Vytorin because your LDL cholesterol is higher than it should be in someone with Diabetes. Blood Pressure of 140/80 is a little high and the suggestion to lower the dosage of Fludrocortisone is a reasonable one. The dose of Fludrocortisone varies from 0.05 to 2.0mg per day so you should discuss this with your doctor. Whether this is a good idea or not depends on your past treatment experience.

I am 32 years old and was diagnosed with Addison's 9 months ago. I am now on 25mgs of hydrocortisol delivered 3 times a day. My blood pressure began rising and I was taken off the florinef because of that. My electrolytes have been monitored by blood tests and are thus far fine. However, my blood pressure continues to be high 145-160 over 90-105 and I have been getting headaches. What should our next steps be? I gained a lot of weight originally probably due to too much prednisone and although now that my drugs are stabilized I am finding it very hard to lose the extra weight. Does being on a synthetic cortical steroid make it harder to lose weight and could the extra weight (I'm about 30 lbs over) be contributing to my high blood pressure?

It is often difficult to get stabilized on your replacement medication. I was uncertain about your cortisol dosage; you mentioned 25mg taken three times per day. I presume the dose is 25mg spread over the three times rather than 25mg three times per day, i.e. 75mg per day. The dose requirement for cortisol varies from individual to individual so even 25 mg may be more than you need.

The fact that you are having weight problems and blood pressure problems suggests that the dose could be too high. You should discuss the problem with your endocrinologist and have her/him check your ACTH and renin on a morning sample before you take your medication to determine whether your dose is correct. Your ACTH should be high before you take your cortisol, usually about 40 pmol/l.

COMMON COLD/FLU/OTHER ILLNESS

I was recently diagnosed with Addison's Disease and find no support. What should I do if I get a cold or stomach flu? When is it necessary to receive intravenous? Any advice you could give me in general would be helpful.

It is difficult to be in a position where you feel you do not know where to turn for support. The first thing you should do is talk to your family doctor about how you feel. There must have been a doctor who made the diagnosis of Addison's disease and prescribed your medication. It would be reasonable to make an appointment with her/him and go over the everyday management of individuals with adrenal insufficiency. If there is an endocrinologist in your area, it would be important to meet with her/him so they will be familiar with your case and can respond more readily if you need help.

A second option, which should NOT replace the first, is to look at the Canadian Addison Society website (<http://www.addisonsociety.ca/faq.html>). There are a lot of questions from other Addisonians and some of them may be similar to yours. You can see if they are of any help.

Finally, if you are on a glucocorticoid (cortisol, cortisone or prednisone), the dose would be sufficient for everyday activities. If you get a cold, the flu, or a significant stress, you should increase the dose by 1/2 or a full tablet of what you are taking or double your daily dose depending on the severity of the situation. If you have gastrointestinal problems for 24 hrs and cannot keep your medication down, then you should go to the hospital emergency dept for intravenous solu-cortef and saline plus some investigation about the current problem. If you do not live near a hospital, you should consider having a kit at home for an intramuscular injection for use in an emergency. The details of this kit can be found on the website and you will have to get your family doctor or endocrinologist to write a prescription for you (<http://www.addisonsociety.ca/emergencyproc.html>, <http://www.addisonsociety.ca/injection.html>)

I am wondering if it is possible to take a herbal product called COLD-FX that is available to help with the common cold. It's designed to help stimulate the immune system. I have Addison's and take 15mg of Cortef a day.

COLD-FX is a special extract of North American ginseng that is marketed to decrease the frequency and severity of symptoms of the common cold. The available studies have been carried out on healthy volunteers and individuals taking corticosteroids were excluded from the study. This exclusion was most likely designed to exclude individuals taking large doses of steroids as treatment for an underlying disorder and not at individuals taking physiological doses as is used in Addison's disease. There is however, no information about its use in individuals with Addison's disease. This is a patented over-the-counter medication and the active material and mechanism of action are unknown. The clinical studies of its beneficial effects are limited.

Since the common cold is a self-limiting problem, it is best to avoid potential complications of taking a compound which is not well defined. Remember, you should increase your hydrocortisone (cortisol) by 1/2 to 1 tablet per day, when you have a cold.

I have recently been diagnosed with Addison's disease. Should I get a vaccination against the flu?

Individuals have different views about getting the flu vaccine. The fact that you have Addison's should not alter your opinion. If you are on appropriate replacement medication, your immune response to the flu vaccine should be normal and you will get normal protection from this year's brand of the flu. It is important to remember that each year new strains of the flu evolve so your protection will not be absolute but vaccination will reduce your chances of getting the flu.

I've got quite a bad cold which is not clearing up easily and I feel very unwell. What should I do?

Take an extra cortisol each day for 2 or 3 days until the symptoms improve. Do not carry on longer than necessary.

I work as a nurses' aid in a large hospital. My job is direct contact with all patients from the emergency room to the Cancer wards. Is it fact that I will easily catch disease because of my low immune system, which is jeopardized because of Addison's?

Addison's disease is most often an autoimmune disease with antibodies damaging the adrenal gland. The remainder of the immune system which is involved in fighting infection is working normally. You should not be at increased risk of getting infections.

How do we treat illness or surgery?

In someone without Addison's, cortisol secretion increases with the stress of illness and for surgery. So the usual clinical practice is to give higher doses of glucocorticoid to patients with adrenal insufficiency in these situations. Unfortunately, there is little information about how much additional glucocorticoid is needed.

"Doubling Up" during Illness: What does it mean exactly? Ex: If on Hydrocortisone 15 mg in am/5 mg in pm - then increase to 30 mg in am/10 mg in pm. You do not double up on Florinef. **How long to double up for?** Generally 3 days and then back to usual dose; if not improving in 3 days, seek medical help.

What is considered an illness? Cold, flu, gastrointestinal illness.

Chemotherapy and Radiation Therapy - What adjustments, if any, are needed for our medications when we undergo these treatments for cancer? It depends - some chemotherapies have steroid as part of the regimen, so may actually decrease glucocorticoid dose. Chemotherapy/radiation weaken immune system, therefore, you may be more prone to infections, therefore, I would hesitate to increase glucocorticoids

CORTISOL DAY CURVE

What about day-curves?

These are common in the UK, but not in Canada. A study from Birmingham compared day-curves to clinical assessment and found the day-curve offered no advantages.

Can you please tell me where in Canada I can go to get a cortisol day curve done on my wife who has Addison's?

A day curve follows cortisol levels throughout the day. For individuals who are not in hospital, this would mean going to the lab every 2 or 4hrs starting at 8am until the lab closes, usually at 6pm. This is most useful in someone who is not on cortisol replacement, since it would provide information about the output of cortisol by the adrenal gland. In someone who is on cortisol it would reflect the levels of cortisol produced by the medication and would depend on when the cortisol tablets were taken. In general, this would not provide much useful information unless there is some reason to be concerned that the metabolism of cortisol is altered. This can occur in individuals on some types of medication such as anticonvulsants. Another way to get this type of information is to do a 24hr urine collection for free cortisol. It would be lower than expected if metabolism is increased. These tests can be arranged at any of the commercial labs.

I was diagnosed 12 years ago with Addison's disease. It appears that my hydrocortisone dose is too high (determined through 24hr urine Cortisol test) and my Florinef is too low. After 4 months I'm still having a terrible time getting the correct dose. I've asked my doctors where I can have a day curve done; they don't seem to know, would you?

You've raised two interesting questions. The first is the value of a day curve in determining your hydrocortisone dose and the second is the role of a 24hr urine in determining your dose of hydrocortisone. When you take hydrocortisone by mouth, it is absorbed rapidly and is metabolized fairly quickly. The blood level of hydrocortisone will fall by 50% over 90 minutes. If you take blood levels of hydrocortisone at two to four hour intervals throughout the day and night, the blood level that you measure will depend on when you took your last tablet. The blood level when you wake up will be low and after you take your morning tablet, the blood level will rise into or above the normal range, then fall as the hydrocortisone is metabolized. Normally, hydrocortisone is secreted at intervals during the day and less frequently during the night, then at increasing frequency starting about 4am anticipating our rising in the morning. This provides variation in blood levels during the day with highest in the morning. A day curve will tell you what your blood level is at a specific time and it depends on when you took your last tablet. It does not help much in determining how much you need. A 24hr urine for free cortisol tells us how much hydrocortisone is excreted in the urine unchanged and in general is a good measurement of how much hydrocortisone is produced during the 24hr period. When we take hydrocortisone tablets, our blood levels may at times be higher than normal and at other times low. This may influence how much hydrocortisone is excreted, so once again, may not help to determine how much you need. The most important thing is how you feel. Dose requirements vary and are influenced by your size, what you do and what other medication you are taking. The right dose for you is the smallest dose that makes you feel well. The dose of Florinef (fludrocortisone) is best determined by checking plasma renin and your blood pressure. A dose of 0.1mg daily is the commonest, but it can vary significantly from person to person. You should review these questions with your family doctor or endocrinologist to be sure there are no specific circumstances in your case that requires different treatment.

CORTISOL MEDICATION

What is the difference between cortisol and cortisone?

Cortisone needs first to be converted to cortisol (=soluortef) before it is active. Cortisol is the active form; cortisone is the inactive form, which needs to be converted in the liver to cortisol; liver must be functioning to convert cortisone to cortisol; about 80% of cortisone is converted to cortisol (25 mg cortisone converts to 20 mg cortisol).

At what times should I take my cortisol replacement medication?

Timing of medication can be an issue for some patients. If taken at supper, and depending on the specific medication, glucocorticoids may cause trouble sleeping. Prednisone has the shortest half-life (length of time before it wears off); Cortef has a mid length half-life; dexamethasone has the longest half-life.

In general, if taking two types of glucocorticoids, for example, Cortef and prednisone, we suggest taking the Cortef when an extra tablet is needed to respond to either physical or emotional stress.

Normal levels show the spikes and valleys throughout the day; they are highest at 8 a.m., 1:30 p.m. and 4 p.m., so replacement medication is often best taken around 7:30 a.m., 1:00 p.m. and 3:30 p.m. Each individual will need to read their own body for optimal timing, as each person's biorhythms are different causing more variations in cortisol outputs

To replace adequately in the Addisonian, it may therefore be necessary to give 30 mg each day, so not to risk under-medicating on the day 30 mg was needed. The sensitivity of receptors also varies from person to person, affecting the dosage required. You will get quicker absorption of steroids without food, although this can cause an upset stomach..

From the moment of stress, it takes a normal body 20 to 40 minutes to respond with cortisol output.

Treatment routines -- examples

	AM	noon	PM	bedtime	Total
cortisol	20 mg		10 mg		30 mg
	20 mg	10 mg			30 mg
	15 mg	10 mg	5 mg		30 mg
	10 mg	10 mg	10 mg		30 mg
	10 mg	10 mg	5 mg		25 mg
	10 mg	5 mg	5 mg		25 mg
prednisone	5 mg		2.5 mg		7.5 mg
	5 mg				5 mg
florinef	0.1 mg				
	0.2 mg				

How do I know if I am taking the right dosage?

The dose of medication for Addison's disease must be discussed with your endocrinologist. The general rule is that "the lowest dose of cortisol that makes you feel well is the correct dose". With respect to Florinef, blood pressure and plasma renin are helpful in making decisions.

The correct dose of cortisol is more difficult to assess, but the smallest dose that makes you feel well is a good guide

How do you monitor glucocorticoid sufficiency?

There is no lab test for this. It is best determined through clinical observation. How do you feel? If levels are insufficient, the Addisonian will have some (or all) of the usual symptoms (fatigue, appetite, nausea, weight loss, aches and pains, emotional impacts). If levels are too

high, there is usually weight gain, the person will have full cheeks, and may bruise easily (especially on the forearms).

Why is it so difficult to get the dose right?

We can never truly mimic the body's normal physiology. When you take your hydrocortisone, the levels rise quickly in the blood and the hydrocortisone binds to the CBG (Corticosteroid Binding Globulin) in the blood. The CBG is quickly saturated, and excess is then present as 'free cortisol' and rapidly excreted in the urine. To more closely mimic natural physiology, it is helpful to take smaller doses more often, such that the CBG binds to the hydrocortisone and then rebinds to the next small dose, giving more cortisol exposure within the body.

Prednisone and dexamethasone are both longer acting synthetic steroids. They bind more weakly to CBG and therefore the exposure in the body is different than for hydrocortisone. Each person may feel best on a different drug – there is no right drug and no lab tests; it takes trial and error to determine what is best for each individual. Different glucocorticoids for different people, and different doses for different people.

I take 10 mg of cortef in the am and 2.5 mg prednisone in the afternoon. Because I had no energy in the morning upon rising, I have recently had to increase my dosage of prednisone to 5 mg. I have since noticed that I am having trouble getting to sleep and staying asleep. Would it make any difference if I took the prednisone in the am, and took the cortef in the pm? I know that prednisone takes longer to 'kick in', but it also lasts longer in the system.

Some endocrinologists like to use prednisone in the treatment of Addison's disease because of its long duration of action to carry overnight. In the non-Addisonian individual, the blood levels of cortisol go down to close to undetectable levels during the night. There is still cortisol inside the cell to carry on the normal activities. These low blood levels may be important to allow the cells to readapt as cortisol is secreted episodically starting about 4:00 AM to get peak levels by about 8:00AM.

I prefer to use cortisol only given two or preferably three times a day usually first thing in the AM and sometime in the afternoon, or AM, noon and late afternoon. This routine would allow you to sleep better. You must discuss this with your endocrinologist. He or she may have specific reasons why you are on the regimen that you are on and they would have to work out the dose of cortisol with you if there is a change.

When switching a patient from one steroid to another (i.e. 0.5mg Dexamethasone to 5.0mg Prednisone), do you suggest weaning? What would you recommend as the best course of action?

0.5mg of Dexamethasone is a little more glucocorticoid than 5mg of Prednisone. I would suggest stopping the Dex and then starting with 7.5mg of Prednisone (1 tablet a.m., ½ tablet p.m.). If all is going well, consider stopping the p.m. half tablet.

Why do you not prefer your patients to take dexamethasone, and instead prefer they take cortisone? I have read that dexamethasone stays in one's system for 24 hours and thus may make someone feel better.

Your question about taking dexamethasone for glucocorticoid replacement is a logical one. The body normally secretes hydrocortisone (cortisol) in small bursts throughout the 24 hrs. The bursts are more frequent starting about 4 AM so that the blood level of cortisol is highest when we get up in the morning. The timing of these bursts is governed by the time we usually rise in the morning. During the day, the bursts are less frequent, so the average blood level falls

throughout the day and is lowest around midnight. These fluctuations in blood levels of cortisol are important in providing adequate amounts of cortisol to the cells without causing excessive exposure. The timing also helps to control blood sugar levels and causes a release of sugar from body stores when it is needed.

Dexamethasone is very useful in situations when continuous glucocorticoid levels are required to suppress inflammation and some other problems, but the continuous exposure of tissues to even moderate doses of dexamethasone over time frequently results a condition of glucocorticoid excess.

By using cortisol in doses spread throughout the early part of the day, we try to mimic to some degree the normal secretion of cortisol and avoid problems such as excessive weight gain, easy bruising and elevated blood sugar.

Is there any problem with taking a combination of prednisone and cortisol daily for my Addisons? Since prednisone lasts longer in the system, I take it in the a.m., and then the shorter acting cortisol in the late afternoon/evening. I've had Addison's disease for 28 years. I am 50.

If you have been taking the combination of prednisone and cortisol that you described for 28 years and have found it satisfactory, there is no reason to change. We recommend using cortisol because it is shorter acting, so blood levels can fall to low levels between doses in the same way they do when the adrenals are working normally. Cortisol is normally secreted in pulses, more frequently in the early hours of the morning and less frequently later in the day, so serum cortisol levels at midnight are barely detectable. These low levels of cortisol are important in preventing excessive exposure of body's cells to glucocorticoids. If you are happy with your current treatment there is no need to change.

Will glucocorticoid cause immunocompromise?

Glucocorticoids will not cause immunocompromise if on a physiological dose. It's only if you are on too much that there will be increased risk of infection. One of the responses to overwhelming infection is increased cortisol production, to prevent the immune system from harming you. Cortisol dampens the immune response so that the body can fight infection but not kill the host. So too much glucocorticoid affects cell mediated immunity. When Addisonians get certain infections (ex. MRSA), it can be hard to find ways to contain the infection in balance with the glucocorticoid, i.e. such that the glucocorticoid does not prevent the antibiotic from working.

What are the symptoms of too much medication?

Symptoms of overdose are the same or similar to the symptoms of insufficient dosage, which is a real problem when fine tuning your dosage. The effects of too high a dose of hydrocortisone include high blood pressure, blood sugar problems (diabetes), increased weight, decreased mental functions; bone density issues/osteoporosis. Symptoms of long-term overdose are similar to the symptoms of Cushings and include weight gain, muscles weakness, bruising, mood change, glucose levels too high.

I have thyroid problems. Will this affect my Addisons med?

Hypothyroidism affects cortisol dosing for Addisonians as cortisol will break down twice as fast and be gone from the system too soon. If you are dealing with thyroid issues, your replacement cortisol dosage may need to be adjusted. If the thyroid function is low, symptoms of tiredness, constipation

and low temperature can occur. (Hypothyroidism causes the breakdown of cortisol to be too slow.) Addisonians should to get regular thyroid and diabetes screening

What about Chronocort?

Chronocort is a new drug under development which hopes to provide slow or sustained release glucocorticoid to better mimic the body's natural release of cortisol. The company is hoping for approvals in 2010.

I've been diagnosed with secondary Addison's due to long term use of prednisone to control sinus problems and polyyps. The endocrinologist advised me to switch from Cortef back to prednisone since I have to take prednisone to control the sinus issues. However, the endocrinologist has left and it is not feasible for me to see a specialist several hours away. Mostly, I know it's up to me to regulate the dosage.

I've been reading a lot about prednisone, and have read that the side effects of Cortef are less, as it does not go through the liver. Also, I read of one person who took 20 mg of Cortef in a split dose and took 1 mg of prednisone in the morning. The small dose of prednisone would help control my allergies and arthritis aches. I feel it is easier to take prednisone as I'm still working full time, and it gives me more energy, but I'm still concerned about which one would be best in the long run. Is there a specific method for switching from prednisone to Cortef?

As well, the lowest dose of prednisone which is effective causes me stomach problems. I did not have stomach problems with Cortef. Would it be possible to switch to Cortef for a period of time and then go back to the prednisone?

The effects of prednisone and cortisol on your conditions should be the same. Prednisone is activated in the liver and has its effect over 4 to 18 hrs. Cortisol is the compound normally secreted by the adrenal and has its effect over 2 to 12 hrs. The fact that prednisone is activated in the liver is not a disadvantage and does not cause any damage to the liver even over the long term. We like to use cortisol in individuals with Addison's disease because the episodic fluctuations in blood levels of cortisol and variation from day to night is what occurs normally and decreases the tendency for over treatment.

If you are going to be on steroid treatment over the long term for your sinus problem, I would agree with your endocrinologist that you should be on prednisone at the lowest dose that controls your symptoms. There is really no benefit to being on a mixture of glucocorticoids.

Glucocorticoids can cause some stomach problems and medication such can to help control them. However, if there were no problems with the Cortef, there should be no problem in switching to Cortef. I prefer it to prednisone for the long term. The conversion dose is 5 mg prednisone = 20 mg Cortef.

I am 38 with fairly regular cycles. Diabetes control is pretty good. My endocrinologist has been unable to tell me what options are available to confirm appropriate hydrocortisone dosage levels. They feel that I should go with what I "feel" is appropriate. Should I expect a different response than this?

It is difficult to be specific about determining the correct dose of hydrocortisone. Our usual answer is a bit like your endocrinologist's. We suggest the right dose is the lowest dose that makes you feel well. The dose of hydrocortisone can vary from person to person – from 10 to 30 mg per day. One test we do is to check ACTH levels before taking your hydrocortisone in the AM. The level should be elevated. If not, you are either getting too much steroid or there may be other factors causing the symptoms. If the ACTH is too high, you may need

adjustments in the hydrocortisone dose. This is not a precise method but it gives you ground rules.

For the Florinef, we measure renin levels first thing in the morning. If the level is high, you may need more Florinef. If it is too low, you may need less Florinef. Once again, these are guidelines to help your endocrinologist decide on making adjustments. The actual decisions require an assessment of the person, not the lab tests, so you must discuss this with your endocrinologist.

I have recently been diagnosed with Addison's disease after being ill for 4 or 5 years. During that period I lost about 15 pounds, and now weigh 97lbs. I also lost a great deal of muscle mass and have very little strength. I have been taking 0.1 Florinef and 0.5 Dexamethasone for about three weeks. The other day I went out for a half-hour walk, and found it quite tiring, but I was kept awake all night by the twitching of my leg muscles. Is this a problem that can be addressed by adjusting my medication or can I expect it to resolve itself through getting used to the medication, or further exercise?

It is good that your diagnosis has been established. Once the doses of your medication get stabilized you should gradually regain your strength and energy and regain your lost weight. Most endocrinologists prefer hydrocortisone rather than the dexamethasone as the glucocorticoid replacement but there is room for discussion. The argument for dexamethasone is that it is long acting and only has to be taken once per day. Since it does not provide the normal fluctuations in glucocorticoid levels throughout the day, even doses that seem in the physiological range usually result in over treatment because the cells in the body are exposed continuously to glucocorticoid. The argument for hydrocortisone is that it is the hormone that the adrenal gland normally produces and is metabolized fairly rapidly. This means that the cells in the body are normally exposed episodically to varying levels of hydrocortisone throughout the day. Hydrocortisone replacement is usually given twice or preferably three times per day with the largest dose in the morning and smaller doses at lunch and in the late afternoon or at dinner. Usually the total dose is 20 to 30mg. "The smallest dose that makes you feel well is the best dose." You should always be sure to discuss your treatment with your family doctor or endocrinologist because each person has different needs and in some cases, other medications can affect the rate of metabolism of hydrocortisone.

I have been told that changing brands of drug might affect the effectiveness of my replacement medications. Could you please comment?

Substitution of drug preparations: Pharmacists will generally give you the least expensive preparation of a drug unless there is a specific request for no substitution. Different brands or generic versions of drugs may have slightly different binders, fillers, coatings, and densities. This might affect your absorption rate. I am not aware of any studies looking at the bioavailability of different preparations of hydrocortisone (cortisol), cortisone, or prednisone from different manufacturers, but it is generally good practice to stay with the same preparation to avoid possible differences in pill content. If you have switched brands and have symptoms of glucocorticoid excess or deficiency, discuss this with your doctor so proper adjustments in dosage are made.

I just went from cortef to 75ug dexamethasone. So far I feel really good, with no highs or lows and good energy all day. Is 75ug a reasonable replacement?

The 75ug dose of dexamethasone is higher than a normal physiological replacement of cortisol. Dexamethasone is long acting - 24 hrs versus 90 min with cortisol. It is difficult to precisely compare doses as I don't know what dose of cortisol you were on before the change. Between 25 and 50ug of dexamethasone is roughly equivalent to 20mg of cortisol, so 75ug of

dexamethasone would be equivalent to about 50mg of cortisol. This is a large dose and because of its long duration of action, it tends to be more likely to result in side effects of too much glucocorticoid. You may be feeling so well because you are getting a higher dose of glucocorticoid than normal. This seems good in the short run, but may not be good in the long run. I prefer not to use dexamethasone for replacement in Addison's disease.

My daughter has been taking hydrocortisone for the past year, due to primary Addisons. As she is experiencing a rapid heart rate and pounding heart, her endocrinologist has changed her to cortisone acetate. I am wondering why he would choose cortisone acetate rather than prednisone. Is there much difference between them? I have not heard of many people on acetate.

Cortisone acetate is frequently used for cortisol (hydrocortisone) replacement. It is inactive itself and has to be converted to hydrocortisone by the liver. The end result should be the same, provided that the liver can readily make this conversion. I am not sure that it is likely to have any effect on your daughter's heart situation. Prednisone is less expensive than hydrocortisone but is longer acting and does not provide the same episodic effect as hydrocortisone given three times a day. The body normally secretes hydrocortisone episodically -- more frequently during the day than during the night.

You and your daughter should discuss the situation with your endocrinologist. I am sure that s/he has done the appropriate heart investigations to rule out any underlying heart problem. S/he can try to explain to you what is actually happening during these episodes and what might be triggering them.

I was diagnosed with Lupus about 8 years ago. Now the doctor says I have Addison's. He changed my prednisone to cortef. I want to know how much prednisone is equal to how much cortef.

It is interesting that you were switched from cortisol to prednisone when you were diagnosed with Lupus. Usually, it is the other way around since the dose of steroid needed to treat Lupus is usually higher than the dose to treat Addison's disease. Prednisone has less tendency to cause salt retention than cortisol, so it is used when higher doses of steroid are needed. The usual dose comparison is 5mg of prednisone is roughly equivalent to 20mg of cortisol or 25mg of cortisone.

Is Prednisone any different than Medrol on the ACTH suppression on the Pituitary, given the equivalent doses, i.e. 6mg of medrol and 7.5mg of prednisone, or 30mg of hydrocortisone?

Medrol is the trade name for methyl prednisolone, it is a little more potent than prednisolone, but at appropriate doses, all three steroids have about the same pituitary suppression. Cortisol is a little shorter acting, so depending how frequently it is given, it may have slightly less suppression of the pituitary. Prednisone and methyl prednisolone are frequently used to treat inflammatory problems such as colitis or some kidney problems because they cause less salt retention and have more potent anti-inflammatory activity than cortisol. They tend to be used in larger doses in these situations and therefore can cause greater pituitary suppression.

It seems that most people are on Cortef. I am 33 years old and I take prednisone 5mg/0.1mg Florinef and lead a great life. I have never had a crisis since the diagnosis 7 years ago. I am active and play all sorts of sports. I was wondering if I should consider switching to Cortef or should I stick to the Prednisone since it's working great. What are the pros and cons of each?

Prednisone and cortisol have similar effects. The reason that we recommend cortisol most of the time is that it is the adrenal hormone that is normally secreted. It is metabolized quite

rapidly so the blood levels drop to low levels between doses and this protects the tissues from too much cortisol exposure. This is what happens normally. The downside to this is that the medication must be taken 2 or 3 times a day.

Prednisone has a longer survival time in the blood so its effects are more prolonged so the tissues do not get this 'on/off' exposure. There are many people who are taking prednisone who are doing well and are happy with their medication. You are obviously doing well so there is no reason to change your treatment.

I'm a 27-year-old female who had a bilateral adrenalectomy to treat recurring Cushing's Disease, I am struggling with low blood pressure and a very high heart rate. I'm currently on 17.5mg of hydrocortisone a day and 0.125mg of Florinef. However, when I wake up in the morning and stand, my heart rate jumps to 150. My resting heart rate first thing in the morning ranges from 90-100bpm. I take my Florinef at 8am, and in the afternoon my heart rate settles down but is still high (75-85bpm while sitting, and anywhere from 100-130bpm standing). I find it's better the later the day gets, but still it's too high. My blood pressure is around 110/72. Is something wrong with my Florinef dose? Should I try taking it twice a day instead of just in the morning? Should I be taking more Florinef?

It is sometimes difficult to get your replacement stabilized after adrenalectomy for Cushing's syndrome. I do not know when you had your adrenalectomy, but there is a tendency to want to get down to normal replacement doses right after surgery in order to get rid of the features of the excess cortisol. Your body has been accustomed to high levels of cortisol probably for a long time. When cortisol levels are brought down to normal, the body has difficulty dealing with this initially, so replacement doses need to be higher than normal after surgery. The amount of cortisol secreted when Cushing's syndrome is active would be at least 2 or 3 times the normal secretion. We tend to start post-operative replacement with doses of cortisol in the range of 40 to 80 mg a day in divided doses and once the post-operative stress has settled down, the dose is gradually lowered. The rate at which it is lowered depends on the response of the individual, but it can take several months to get down to a normal dose level.

The replacement dose of cortisol can be quite variable from individual to individual. It can be as low as 15 mg a day or as high as 40 mg. The average is from 20 to 30 mg. The dose of Florinef required ranges from 0.1 to 0.2 mg a day but it is important to balance the dose of Florinef once the dose of cortisol has been determined.

Your current situation depends on when you had your surgery and how this relates to what I have described. You must discuss your problems with your endocrinologist because there may be factors that I am not aware of that have an impact on your medication requirements.

I am a 63 year old male [200 lb] diagnosed with Cushing's five years ago. I had both adrenal glands removed and was put on a dose of 40 mg/day hydrocortisone and .05 florinef. My physical symptoms of Cushing's gradually disappeared and I did begin to feel much better and regained some quality of life. Today, I am much stronger physically, but suffer extreme fatigue and a lack of stamina which severely limits my quality of life. My eyes bother me often and I usually have daily bouts of generalized body pain especially, if I have been active. I still have no drive, energy, or ambition - Is this depression or Addison's? I have tried varying doses from 30 to 40 mg/day in all manner of configurations and timing with no real improvement in well being. I see my endo every 6 mo. and have a pile of blood work done which all is basically normal. At my last visit with my endo, she suggested this may be as good as I get and I may have to live with it. I am now in the process of lowering my dose to approx. 30 -35 mg/day. Any suggestions would be greatly appreciated.

When you go through the sequence that you have been through it is difficult. I am not sure how long you had Cushing's syndrome before you sought help but it is probable that it was several years before you were aware of your problem. The excess cortisol, over a long period of time, causes a loss of protein from your tissues including skin, and muscle. It can also cause emotional problems. When the high levels of cortisol are brought down, your body has to readjust. We usually leave individuals on slightly high doses of cortisol after surgery to avoid a dramatic change, then lower doses gradually to maintenance levels.

It can take a long time to return protein levels in muscle and skin to normal and to return calcium levels in bone to normal. It can also take a while to return the emotional state to normal. From your description, it sounds as if you have gone through many of these changes successfully. I think you will continue to improve. It will help to slowly build up your muscle strength with simple exercises. As your stamina improves, your confidence will improve and you will have more enthusiasm to do things.

Your dose of cortisol to date has been reasonable. You may be able to decrease it a little. With your size, 30 mg of cortisol is about average, but requirements vary from person to person. Three times a day dosage is usually the best. The dose of Florinef can be checked by measuring your plasma renin. I am sure your endocrinologist has reviewed these things with you.

The phases you have gone through are not unusual in recovering from Cushing's syndrome. There is likely to be further improvement. You need to be patient and you should try to be as active as possible.

What about dermal patches instead of pills?

Dermal patches are not an appropriate delivery mechanism for cortisol. Due to the physical properties of the patch and skin, the absorption is even; absorption does not increase or decrease with stress.

I have secondary Addison's due to long-term steroid use for another problem. ACTH stimulation in hospital determined that my adrenals are working; it is my brain that won't wake up. Without the ACTH stimulation, I produce almost no cortisol. I am now taking 22.5mg of cortef, and my endocrinologist advised me to reduce by about 2.5mg per day, perhaps a month at a time. I was taking 25mg before the hospital stay and felt OK. It is only 2 weeks later but I'm feeling pretty miserable.

There is still a question as to whether I will be able to stop taking cortisone of some form due to chronic sinusitis and polyps. When I head back to work, I expect I'll catch something, and need to increase then decrease my dosage again. Also, I am prone to various infections when I lower the dose.

My endocrinologist here is leaving and he doesn't seem to think I need a referral to another one – I should be able to handle this on my own with the family doctor (who was not familiar with cortef before I was referred to the specialist). Should I ask for a referral to another endocrinologist or can I handle this on my own?

Your problem of secondary adrenal insufficiency is fairly common because people are treated with high doses of steroids for problems such as asthma, chronic obstructive lung disease, arthritis, and colitis. As you have noted, the steroid (usually prednisone) suppresses both the pituitary and the adrenal. The only way to revive these glands is to gradually lower your dose of steroid until it is slightly below the level your pituitary would like to have and it will gradually start to recover and produce ACTH. The plan that you are following is a reasonable one. Another

plan is to cut your dose by 1/2 a tablet one day per week and stay on the previous dose the other 6 days. The next week cut back by 1/2 tablet two days per week. You can level off at any time until you feel comfortable proceeding. How far and how fast you go will usual depend on why you were on the steroids in the first place.

The time that this process will take varies with the dose of steroid that you have been on, the length of time that you have taken it, how it is withdrawn, and probably some individual factors. The studies that have been done on this have shown that it can take from several months to several years before recovery is complete and the response to stress is adequate. This process should be supervised by an endocrinologist because there are bound to be some setbacks along the way which have to be dealt with. There will also be the decision as to whether you are able to respond to a stressful situation such as appendix surgery etc. This can require experienced judgement.

Remember if you have been on high doses of prednisone or cortisol for a significant length of time you need to protect your bones from osteoporosis. You should discuss this with your endocrinologist.

Should I be concerned about recent lab work I had done, with the result showing a high reading of 51 ACTH, as well as a high reading of 829 cortisol? My GP said to wait and discuss it with my endocrinologist, whom I don't see for another 4 weeks.

I am assuming that you have Addison's disease and that you are taking cortisol (cortef) as your glucocorticoid replacement. When ACTH is measured on a morning blood sample, the levels are almost invariably high. The upper normal level for ACTH in most labs is 10 pmol/l and levels of 30 to 75 are usually found on a morning sample before taking the cortisol. The cortisol level is usually low in the morning before taking the cortisol and peaks 1 to 2 hours after taking the medication. The normal range after taking medication is up to about 600 nmol/l depending on the lab, but this can be affected by the protein that carries cortisol in the blood. The most common medication that affects this protein is estrogen found in the birth control pill or in hormone replacement therapy. Under these circumstances, cortisol levels can be up to 1000 to 1200 nmol/l. The cortisol that is bound to the protein is not active so if you are taking the appropriate dose of cortisol there should be no problem.

I have Addison's - my adrenals bled out internally from heparin and fragmin. Should a person take an herbal adrenal support? I've been taking 25mg cortisone acetate with breakfast and 12½ mg cortisone acetate at supper, plus Florinef 0.1mg every other day since December 2004. Should I be on 20mg of hydrocortisone divided throughout the day? I'm tired, my hands and feet bones are becoming weaker, eyes etc.

The dose of cortisone acetate and Florinef that you are on would be considered a reasonable replacement dose and the twice a day dosage is appropriate. In most European studies, virtually all of the individuals are on cortisol rather than cortisone, but theoretically, since cortisone is converted to cortisol, this should not make much difference. The general rule is that the lowest dose that makes you feel well is the right dose for you. It depends on several factors including size and weight. You can discuss with your doctor the possibility of lowering the dose of cortisol to 25mg daily. Taking 12.5mg in the AM, 6.25mg (1/4 tab) at lunch and 6.25mg in the afternoon. Depending on age etc., it may be worth checking your bone density. Once again, check this out with your doctor. There are no herbal preparations that can replace your adrenal hormones.

I'm 44, diagnosed 30 years ago, my daily dosage is: 25mg cortisone acetate morning, 12.5mg evening, and 0.1mg florinef. With a history of crises during hormonal adjustments in my body (puberty, pregnancies and pre-periods), I'm cautious as I approach menopause years. I'm keen

on preventing osteoporosis, yet I'm nervous about how my body would handle a further reduction in cortisone intake. Are Addison patients recommended to gradually reduce cortisone intake as our bodies slow down? Should I be considering this? I take calcium supplements - is there a recommended dosage for adult female Addison patients?

The average dose of glucocorticoid is 37.5 mg of cortisone or 30mg of cortisol (hydrocortisone). The dose is usually taken twice a day as you are doing, but it is probably better to spread it out to three times a day e.g., 12.5/12.5/12.5. The dose requirement is quite variable from individual to individual so a dose of 25mg cortisone daily is not unusual. This is related to the fact that tissue receptors for cortisol vary from person to person. We always say that the right dose of cortisol or cortisone is the lowest dose that makes you feel well. It is also important to be sure that the dose of Florinef is also optimized. The best way to do this is to have your doctor measure your plasma renin. When you change doses of cortisone, it is not unusual to feel less energy for a while, but remember, we all feel better some days than others, so don't blame everything on the cortisone.

I was diagnosed with Addison's disease, and for many years was well maintained on a dose of 5mg Prednisone and 0.1mg Florinef. After a few years, my endocrinologist felt that I could be quite reasonably managed by my family physician, with whom I have a very good relationship. Approximately 6 years ago, under the care of my family physician, my prednisone was increased to 6mg once daily (taken in the morning) due to a re-emergence of increased fatigue, mild nausea, occasional dizziness, and vitilago. Since that time I have been quite well. At 50 years of age, I exercise regularly, eat well and have no difficulty maintaining a healthy low body weight or maintaining a low Bp; fortunately, I require no other medications apart from calcium replacement and ostoforte. I have two questions:

- **Do you recommend periodic reassessment by an endocrinologist even in the apparent absence of complications?**
- **I notice in the frequent Q & A that very few patients appear to be taking prednisone. While recognizing that treatment is very individual specific, is there a general preference at this time re: use of prednisone?**

First of all it is good to hear that you are doing so well. When things are going well, it would be a bad idea to break up a winning team. If you have a good family doctor, who understands the situation, there is no reason why she/he cannot look after you. If you have a problem your family doctor is not comfortable in dealing with, you can be referred back to your endocrinologist. You should have an endocrinologist who knows you, so if a problem comes up, she/he will not have to start from scratch in sorting it out.

There is no major problem in the use of prednisone for cortisol replacement. It is longer acting and some people like it for that reason. The reason that cortisol is preferred is that it is shorter acting and if taken two or preferably three times per day, it provides a better approximation of the normal cortisol production. Cortisol is normally secreted in bursts at intervals throughout the day and night. In the intervals between bursts, cortisol levels drop and it is felt that these low levels may be important in preventing an excessive effect from the cortisol. Since prednisone is longer acting, it is more difficult to simulate these conditions. In your case, you are taking the prednisone once daily and are getting along well, so I don't think you should change.

I had both of my adrenal glands removed due to the spread of lung cancer. My lung cancer has been under control for 3 years now. No chemo or treatments. I am now taking 75 mg of cortisone a day and 0.01 mg of florinef. My family doctor says one thing and the endocrinologist says another, while I suffer with this problem. I feel tired most of the time. Any small jobs I try to do really tire me out. Are there any special tests I could have done to correct my problem?

Your situation is more complicated than a loss of adrenal tissue. If you are being treated for the lung cancer, both the treatment and the underlying problem could cause fatigue. From the standpoint of your adrenal status, you should be on cortisol and florinef. The dose of cortisol should normally be between 15 and 30 mg/day and the dose of florinef between 0.1 and 0.2 mg/day. The tests that will guide your doses of medication (but will not give you absolute criteria) are - blood pressure, electrolytes (sodium, potassium and chloride) and renin for the florinef and a morning ACTH which should be slightly high for the cortisol. Your endocrinologist will probably have already done these tests so you can review them with him/her to be sure everything is in order. Unless there is something you haven't mentioned, a dose of cortisone of 75 mg/day is too much for adrenal replacement. Cortisone at those doses has a tendency to decrease muscle build-up and cause protein loss - causing things like thinning of the skin and bruising. I don't know what you are hearing from your physicians, but they should be talking to each other and to you to explain their views. You should not be caught in the middle.

CRAMPS

I read, with interest, the letter to the Doctor in the June 2006 Newsletter. It included various questions, but the one of interest to me was not answered. This lady had problems with leg muscle twitching after she went to bed. I also experience this and would very much like to know if other Addisonians do as well, and I also would like to know what causes this, and/or what can be done about it?

Leg cramps and muscle twitching at night are relatively common complaints in the general population and I am not aware that individuals with Addison's disease are more likely to have these problems. You could discuss this with your family doctor to be sure your sodium, potassium and calcium are normal. Sometimes increased or unusual activity will cause these symptoms temporarily. If this is a problem which is interfering with your sleep, your family doctor may want to do some further studies or try you on some medication to relieve the symptoms.

I was diagnosed with Addison's disease 2 months ago. I was put on 25mg of hydrocortisone (15mg in morning and 10mg in evening) and 0.05mg of florinef. Since becoming unwell, I have experienced muscle cramping and joint pain. Is this to be expected or is there anything I can do to help alleviate this problem? As well, I would like to become pregnant and am wondering if there are any extra measures I should take to ensure a healthy pregnancy.

I was not sure from your question whether the muscle cramps and joint pain began before or after you began taking the cortisone. It is rare but some individuals get muscle pain when they start taking cortisone and it usually passes with time. If this is the case, you could try cutting back on your cortisol for a day or so, then go back to your current dose.

If the pains began before starting the cortisol and did not improve on medication, you should have your doctor look at your joints to see if there is evidence of inflammation and check your blood electrolytes and calcium to be sure these are normal.

You should be sure your treatment for adrenal insufficiency is stable before trying to become pregnant. Once it is stable, there should be no adrenal factors that would interfere with you becoming pregnant. Your cortisol requirement may go up a little during pregnancy so you may have to increase your dose by 1/2 or 1 tablet daily.

You should always check with your doctor before you make any changes in your medications.

DIABETES

How does cortisol interact with glucose/insulin?

Cortisol decreases the effect of insulin, less effect of insulin results in increase of blood sugars.

Are there special difficulties coping with Addisons and diabetes type 1?

Yes. Addisonians must take a glucocorticoid to control the Addisons. This will make control of the diabetes much more difficult. When you take your medication in the morning, this raises glucocorticoid levels above normal physiological levels. This will affect your insulin sensitivity. Your insulin will not be as effective when your cortisone levels are a little high as compared to when they are a little low. When your cortisol levels are a bit high, you require more insulin. When your cortisone levels are dropping, you are more prone to hypoglycemia. Addisons makes type 1 diabetes hard to control. You must be on modern insulin regimen (rapid acting insulin analogues, more with earlier meals, cautious about background insulin levels). It is easier to become hypoglycemic when glucocorticoid levels drop overnight.

My father was diagnosed with Addison's years ago and has also developed diabetes. He has been losing weight since the diagnosis, but in the past couple of years, has dramatically dropped in weight to about 112lbs on a 5'8" frame. What can he eat that will help him gain but not effect his diabetes? Should he increase his cortef/cortisol? He is under a great amount of stress right now, so I did not know if more medication might regulate things better.

The combination of Addison's disease and diabetes presents two separate but interrelated problems. The Addison's disease should be treated with a combination of hydrocortisone (cortisol) and Florinef as in other situations. The lowest dose of cortisol that makes him feel well is the best dose although this may be a little hard to determine if his diabetes is not well controlled. First of all, he should be followed carefully by an endocrinologist. He should be on a standard dose of cortisol (eg 20mg AM, 5mg at noon and 5mg at 4PM) and Florinef depending on his blood pressure (eg 0.1mg). If he is losing weight while he is eating a reasonable diet, it is likely that his sugars are not well controlled and his diabetic medication may require adjusting. Since his weight is so low and he is still losing weight he probably requires insulin if he is not on it already. This is a complex situation so he must have these decisions supervised by his endocrinologist.

I am struggling trying to keep my weight down as I am also diabetic and just newly on insulin. I keep gaining weight. I am on cortef. What can I do? I am on 15 mg of cortef, I go to the gym 4 times a week, walk over 10,000 steps a day, and am very careful what I eat because of my diabetes. Nothing is helping. I do all the exercise I can do, and don't know what else to do.

Being careful about what you eat does not mean that you are eating the number of calories that you require to lose weight. There are genetic factors that influence body weight so that the number of calories eaten by one person may result in weight gain while another person eating the same number of calories may actually lost weight. You have to cut back on your intake and increase your activity to find what works for you. As you cut back on your food, your blood sugars will come down so you will have to make adjustments.

I am assuming that you are on cortef because you have Addison's disease. If you are gaining weight, there are a variety of possibilities:

1. You are on more cortisol than you need.
2. You are not as active as you should be.
3. You are taking in too many calories.

The easiest of these possibilities is the dose of cortef. The dose requirement for cortisol is variable from one person to another, usually between 15 and 30 mg per day. The lowest dose that keeps you feeling well is the best for you. Too much cortisol will also make your blood sugar more difficult to control so it is worthwhile taking a careful look at it.

Being careful about what you eat does not mean that you are eating the number of calories that you require to lose weight. There are genetic factors that influence body weight so that the number of calories eaten by one person may result in weight gain while another person eating the same number of calories may actually lose weight. You have to cut back on your intake and increase your activity to find what works for you. As you cut back on your food, your blood sugars will come down so you will have to make adjustments.

I was just put on metformin for high glucose but don't know why it is high all of a sudden. The metformin seems to be working but, before that, I was gaining 5-6 pounds a week. I also did a 24-hour urine test and the cortisol was in the limits but on the low side. I am exhausted and everything directs me to Addison's. Is it possible to gain weight with Addison's?

It is possible to have both diabetes and Addison's disease but it seems unlikely in your case. A gain of 5 to 6 pounds per week suggests fluid retention, since it would require a very large number of calories to add that much weight in fat tissue. If the sugar is not getting from the blood into the cells, one of the symptoms would be fatigue and this may take awhile to improve after the metformin has started to work. Addison's disease is a possibility but unless there are other features to suggest this diagnosis, I would tend to focus on the treatment of the diabetes.

My daughter was diagnosed with type 1 diabetes at age 14 and Addison's disease in September 2006 at age 17. She is currently taking Cortef 20mg in the morning and 10mg before supper. In February 2008, her blood pressure crashed, and her endocrinologist put her on Florinef 0.05mg in the morning. Further, my daughter must have had at least 100 hypoglycaemic seizures since 2006.

The medication that your daughter is on for her Addison's disease - Cortef 20 mg in the AM and 10 mg at supper plus 0.05 mg Florinef daily - should be about right. My major concern would be her diabetic treatment. The hypoglycaemic episodes have to be related to her insulin/diet/activity regimen and this should be reviewed with your family doctor or endocrinologist. You should review the times of day that the low blood sugars occur, what type of activity she has been doing in the hours before the episodes and when and what she has eaten. She should also be checking her blood sugars before meals and at bedtime to determine how much insulin she needs. You may be able to determine a pattern that will help you and your endocrinologist to determine how these can be avoided.

My biggest issue is an unquenchable, unrelenting thirst throughout the day and night, causing me to wake several times each night to drink and urinate. It's difficult to sleep leading to extreme fatigue. Muscle spasms and high/unstable blood pressure are also issues. I have Hashimoto's Thyroiditis and pernicious anaemia. Amaloride and Vasotec were discontinued after diagnosis of Addison's disease. Something just is not right in the medications mix maybe contributing to thirst.

You have recently been started on cortisol for Addison's disease and are now thirsty. When someone presents with increased thirst and increase in urination, the first question would be "what is the blood sugar?" This is particularly relevant because you have recently been started on cortisol in a fairly large dose and this could bring out a latent tenancy for diabetes. Hashimoto's thyroiditis and pernicious anaemia are autoimmune diseases as is Addison's disease so they frequently are present in the same individual.

I'm a 58-year-old male. I was diagnosed with Addison's and hypothyroidism when 24, and with diabetes 25 years later. I've normally been fine unless dealing with the flu or other issues. In 2007, I was admitted to hospital with fever and chills - an Addisonian crisis - and it took 5 days before I was stable enough to leave. I lost consciousness twice before reaching the hospital and had no BP reading on arrival. The cause was never found, and it was diagnosed as fever of unknown origin. I went back to work but didn't have as much energy, etc as before this incident. Last November, I was admitted to hospital again, again with fever and chills and adrenal crisis. I was in and out of hospital several times, again very ill, and tested for everything you could imagine, and again there was no diagnosis beyond fever of unknown origin. After one hospital stay, I was given so much fluid that I went into mild heart failure - had legs like tree trunks. I went back to work eventually - after losing about 25 pounds (seemingly diabetic-wasting following very high steroid doses in the hospital) but couldn't cope after 2 months of struggling. I am now applying for long-term disability. I'm on 5 doses of insulin daily now and still having a hard time with my sugars.

I always feel slightly depressed when I hear that someone has had to go on long-term disability because of complications of a medical problem which they have dealt with effectively for over 25 years. In your case, you have three related disorders and have been able to manage everyday health issues along with your work for all these years. It is frustrating that something is now going on which has changed your life.

You have Addison's disease, chronic thyroiditis and Type 1 diabetes mellitus which are part of an autoimmune syndrome in which each of these endocrine glands has been damaged by antibodies directed against a specific protein in each gland. Treatment of the thyroid problem is usually straightforward and once the proper dose of thyroxine is established, the dose remains stable over long periods. The diabetes and Addison's disease are a different matter.

You are on 5 injections a day of insulin, so you are probably checking your blood sugars frequently to regulate the insulin doses. As I am sure you have noted, sugars tend to go up with infections and this requires adjustments in insulin doses. You do not have to keep your sugars perfect during these periods but you do not want them to be too poorly controlled.

During infections, there are also effects which influence your adrenal glands. With the fever, there is a loss of sodium in the urine so you need to increase your salt intake. The stress of an infection also increases your need for hydrocortisone so you must increase the dose of hydrocortisone that you usually take. How much to increase the dose is always a question, but I like to suggest that you "think for your adrenal gland". For a minor illness such as a cold, the dose can be increased by ½ tablet a day until things return to normal. For more major problems such as the flu, an increase of a full tablet or a doubling of the usual dose would be appropriate. This type of dose increase for a few days will not do you any harm!

A more difficult situation occurs when you have gastrointestinal problems. If for more than 24 hrs you cannot keep your hydrocortisone down, you should go to an emergency department, and show them your information card which you should have in your wallet, stating that you have Addison's disease and that you need solucortef and saline first and then investigation to determine the cause of your current problem. If you cannot get to an emergency department easily, you should have an emergency kit with solucortef at home and have someone there familiar with how to give it to you. This contains 100mg of hydrocortisone and will sustain you until you get to an emergency department. A slightly elevated dose of hydrocortisone should be continued until your situation improves. *(Ed note: see a sample letter for use in emergencies, as well as information on emergency injection kits, on our website at www.addisonsociety.ca.)*

If all of these avenues have been followed, and you are left with an unresolved situation, you should review the problem with your endocrinologist. S/he may want to be certain that there is not some other autoimmune problem which could be contributing to your current situation.

DIAGNOSING ADDISONS

How can my doctor diagnose Addisons, and is it often misdiagnosed? Also, are there other diseases with similar symptoms? I have had these symptoms for a long time and they are now becoming very overwhelming; I am having a difficult time managing them

In the early phases, the symptoms of Addisons can be non-specific. Weakness and fatigue are common to many illnesses. Some of the specific signs such as skin pigmentation may only come on as the disease progresses, and in secondary adrenal insufficiency there is no skin pigmentation. It is a situation where your doctor has to think about the possibility of the problem and then do some testing. If you bring your concerns to your doctor, she/he can discuss with you whether testing would be appropriate. The screening tests for Addisons are a serum cortisol and ACTH. The results of these tests will help to determine whether other testing is indicated.

Does having Addison's disease increase risk for (grand)children, siblings?

It depends on the cause: if cause of Addison's disease is bleeding into the adrenals, tuberculosis, medications, cancer spreading to adrenals, then no. If cause of Addison's disease is due to antibody destruction (most common cause in North America), then yes.

I have just recently been diagnosed with Addison's so I still have a lot of questions. I was told that when you have this, you have a very hard time getting pregnant, but I just had a baby 12 months ago with no complications. Is this hereditary? I am usually very active but lately can't do much without getting dizzy and feeling awful. Once on meds, will I be able to participate in all the sports I used to?

I will try to give you some general advice but you should sit down with your endocrinologist with a list of questions you want answered. This may take more than one session but you can do it while you are getting your cortisol and Florinef doses sorted out.

Addison's disease by itself will not cause you any problems in getting pregnant. Some individuals with Addison's disease can also have autoimmune involvement of the ovaries but this only occurs in about 10% of cases.

Once your dose of cortisol and Florinef are stabilized, you should be able to get back to your old self. This can include various athletic activities that you enjoy. Your problems with dizziness should also resolve.

Some autoimmune diseases tend to run in families, but if you have Addison's disease by itself, I don't think that this will be a problem.

All of these comments are based on the understanding that you have primary adrenal insufficiency (Addison's disease). There are other types of adrenal insufficiency and you should confirm your diagnosis with your endocrinologist. I mention this because you told me that you had a baby about 12 months ago. After complicated deliveries, it is possible to develop a pituitary problem which can cause secondary adrenal insufficiency. These individuals do not have the skin pigmentation seen with the primary type.

I am currently being investigated for Addison's Disease. I am 35 years old, female. My father had Addison's Disease and my mother's first cousin also has Addison's Disease. Parts of my hands, wrist, and shin have patches of hyperpigmentation and my blood values indicated an ACTH value of 156 (my doctor said normal was under 10). Sodium, potassium and cortisol were normal. I have to wait 3-6 months to see a specialist and I am confused if this is a strong or weak indication that I may or may not have Addisons.

An ACTH of 156 pmol/l is very suggestive of Addison's disease. You should have the test repeated to be sure there was no lab error. It should be done in the morning before 9AM, A serum cortisol should be taken at the same time. If the cortisol is low (under 100nmol/l) and the ACTH is high, that is convincing evidence that you have Addison's disease. If your family doctor phoned the endocrinologist and told her/him these results, you should be seen within the next week or so. The high ACTH suggests that you do not have any adrenal reserve. If you cannot get to see the endocrinologist, then your family doctor could start you on cortisol

I've been struggling for a year with my health and need some answers. I've lost over 60 pounds, have abdominal pain, fatigue, and fuzzy head (among numerous other symptoms). I am 34 years old and have three boys; I really need to get healthy. My doctor was almost sure she'd find something with a 24-hr urine cortisol test but it came back within 'normal' range. Could the test have been affected by some extremely stressful things happening at that time? The morning I started the test, one of my favourite pets died unexpectedly and I also had a family emergency. I'm concerned that my cortisol levels might have shown as normal instead of low because of what was going on. Should I ask for another test?

I am not sure whether the symptoms you have could be related to adrenal insufficiency or not. It depends on what other things are found when your doctor takes your complete history and reviews your physical exam. A single 24-hr urine collection does not rule out adrenal insufficiency because the amount of cortisol that you made that day may be the maximum cortisol that your adrenals can make. The best tests to diagnose adrenal insufficiency are a serum ACTH and a serum cortisol and an adrenal stimulation test in which 250ug of Cortrosyn (synthetic ACTH) is injected intravenously and blood samples for cortisol are taken before and after the injection to see if your adrenals can respond to the stimulation. You will have to discuss this with your endocrinologist to see if her/his findings would suggest this investigation.

I have been feeling unwell for months. I am extremely tired, weak, out of breath, despite decent physical conditioning, nauseous early in the day. I have lost about 15 pounds in the last 2 months. I do not think I have dark skin, but I do have the same sort of blotchy complexion on my face that my sister had when she was pregnant. Blood work has been fairly normal. Once my potassium was high, but it came back to normal. My AM cortisol level was 143 nmol/L. As that's in the normal level, I was told that it wasn't my adrenal glands. My TSH was slightly elevated once (5.22) but quickly came back to normal. I was wondering if you think that my symptoms could match at all to Addison's?

It is always frustrating when we cannot seem to get to the bottom of a problem. In adrenal insufficiency, the lab tests are often normal in the early phases of the disease. The cortisol of 143 nmol/l has to be interpreted based on the time of day that it was taken. For a morning sample this value is on the low side. For a late afternoon sample, it would be normal. A morning cortisol over 300 nmol/l would be against a diagnosis of adrenal insufficiency, but the best way to test for it is to measure both cortisol and ACTH on a morning sample. If there is any uncertainty, cortisol can be measured before and after the injection of ACTH. This last test is usually done by an endocrinologist.

The fact that your tests have been changing at different times raises the possibility that you might have had a virus infection affecting your thyroid. These tests generally return to normal as the infection clears.

I am not sure if I have Addison's or if I am heading in that direction. I have had two cortisol saliva tests and both came back below normal limits on 6am and 12 midnight levels. I feel like I have a bad hangover most of the time and moderate depression (I am a non drinker) but start to feel better after 6pm every day. If not early stages of Addison's then what else could this be? I have tried many herbal remedies and glandulars which worked for a short time then stop working after a few days. My doctor put me on very low dose cortef but I felt worse after taking it.

The symptoms you have described are quite non specific and could be associated with a variety of problems. None of the labs in this area measure salivary cortisol so I am not sure how accurate the values are that you have had. If they are done well, they are very good. The most satisfactory way to diagnose adrenal insufficiency is to measure cortisol and ACTH levels. In Addison's disease, the problem is in the adrenal gland and ACTH levels will be high in attempting to make the adrenal work harder. If the problem is in the pituitary gland, both cortisol and ACTH will be low. If you are taking cortisol, the tests will be difficult or impossible to interpret. You should discuss the situation with an endocrinologist who can assess both your symptoms and your physical examination and help to suggest further lab work or suggest other possible causes for your symptoms.

Does Addison's disease hit all at once, or does it come on slowly?

Addison's disease usually comes on gradually over several years. Once the adrenal damage reaches a critical stage, individuals can become ill quite quickly. Weight loss is a common symptom, but diarrhea, chills and back pain are not usually associated with Addison's disease. Skin pigmentation is a common feature but may not be obvious in some situations. If there is a family history of Addison's disease or other autoimmune diseases such as thyroid disease or diabetes, or if you are worried about this problem, you should talk to your family doctor. The best test to rule out the diagnosis is a serum ACTH. The ACTH goes up as the adrenal is starting to fail because of damage by antibodies and is elevated when serum cortisol and other tests are normal.

What causes autoimmune disorders?

We don't know. Autoimmune simply means that the body attacks itself. The immune cells of the body all go through the thymus, which is where the cells learn to recognize 'self', what is host, what is not, and to attack foreign cells, not self. Autoimmune means lack of tolerance to self; something happened in the programming of immune cells in teaching them to leave self alone.

Is congenital adrenal hypoplasia (CAH) the same as Addison's Disease?

CAH is an uncommon problem in the development of the adrenal due to an abnormality on the X chromosome. It presents either at birth or shortly after with salt loss and failure to thrive.

At what time of day should I get a cortisol blood test?

The time of a blood test for cortisol levels matters: the normal readings at 8 a.m. would be abnormal if the blood was drawn at 3 p.m., and visa versa. We should always mark down the exact time of our blood tests, to inform our doctors when interpreting results, as the labs often fail to note the time.

I am 44 years of age. I have a long and complex medical history with many problems, including a kidney transplant at age 35. By 40, I dispensed with most of my doctors and medications, except prednisone, and learned much more about natural health. Five weeks ago, I was working hard, and did not eat a lot. I eventually collapsed, almost lost consciousness, hurt everywhere, and began to throw up. The next day, I could barely stand, and was vomiting blood. I got to the E.R., where luckily an endocrinologist knew what was going on. He gave me 100 mg hydrocortisone. The next day, he told me I had Addison's. However, a week later, my GP told me that I do not. He was not sure what went on, but told me I had an Addisonian-type crisis, because I had over exerted myself and missed one day's worth of 5 mg prednisone, which had been transplant protocol. I went back to the endocrinologist, who twice confirmed that I have Addison's Disease. Today, my family doctor had the letter from my endocrinologist, but he does not tell my family doctor that I have Addison's. What is going on here?

Your encounter at the hospital was in some ways a fortunate one since it brought your adrenal situation to everyone's attention. I think both your doctors are correct; they are focused on the term 'Addison's Disease'.

If I understand correctly, you have been on prednisone since your transplant 13 years ago. The current dose is 5mg and may have been higher in the past. During the past 13 years, your adrenals have not had to work because you were getting all or nearly all the glucocorticoid (hydrocortisone like compound) you needed from the prednisone. Your adrenal glands are probably suppressed because they have not been working as long as you have been on prednisone. When you missed your prednisone that day and probably did not have an adequate fluid intake, you had an "adrenal crisis". This just means you did not have enough hydrocortisone in your system. In your case, this was due to long term adrenal suppression; in other cases, it is due to the fact that the adrenals have been damaged by infection, antibodies or a variety of other causes. This is generally referred to as Addison's disease. When the adrenals have been suppressed, as in your case, it is not usually called Addison's disease, but since the result is the same if you miss your medication, sometimes we refer to it as an Addisonian crisis.

As you can see, your doctors were not really disagreeing about your problem, they were discussing the semantics of what to call it.

For the past year, I have had increasing episodes of dizziness, two of which resulted in falls. My body has felt weak and I have had several infections, both respiratory and bladder. My family doctor did a cortisol test which came back as being very low. An endocrinologist repeated the morning cortisol level, agreed that the cortisol was low, and suggested an insulin hypoglycaemic test, after which she informed me that I have cortisol insufficiency. She now wants to do an MRI of my pituitary gland. She has also prescribed Cortef 10mg twice a day for at least one year. Initially she thought the problem was Addison's disease which I understood was an adrenal insufficiency. Why is an MRI being performed? Is Cortef a safe drug to take for cortisol insufficiency? I am a bit concerned about taking a steroid for such a long period of time, as I have heard that they can cause weight gain etc. I will talk to the endocrinologist to get more answers. Does this sound like Addison's disease or are there other causes for cortisol insufficiency?

The fact that your cortisol response to insulin induced hypoglycaemia was low, would be in keeping with adrenal insufficiency. This problem can be due to destruction of the adrenal glands or to a problem in the pituitary gland which controls the adrenal gland by its production of ACTH. Usually ACTH is measured along with cortisol during the insulin test and this helps to determine the cause of the problem. The MRI is done to visualize the pituitary if there is any concern that you could have a pituitary problem. I am glad that you are going to talk to your

endocrinologist to find out exactly what was found during testing. If it was shown that you have adrenal insufficiency, the treatment is usually lifelong. Your endocrinologist will follow you, be sure the dose is correct and you should not gain weight. If the problem is in the pituitary gland, you would require other investigation and treatment. It is important to discuss the tests and the treatment with your endocrinologist so you truly understand the cause and the management of the problem so you will be able to make the right decisions if you have any problems in the future.

I had a right adrenalectomy 4 years ago. After surgery, my left adrenal and pituitary glands shut down. I was placed on prednisone, and six months later, was off of it, as my glands "woke up" and were functioning fine. Last year, I noticed some symptoms similar to Cushing's syndrome but also had these with the tapering of prednisone: weak, aching muscles; a few times my legs felt like they would buckle; headaches; blurred vision; nausea; vomiting after a glass of wine and a meal. There is one little difference - I have noticed a few scars have turned a brownish colour; not all my scars but one in particular that has been there for 5 years has turned this colour. My blood pressure is normal, I have only lost a few pounds in the past week, but I have had diarrhea, similar to what I experienced when I tapered the steroids after surgery 4 years ago

Does this sound like a return of Cushing's or Addison's? I realize diagnosis is difficult without testing, but I am wondering is it possible that my other adrenal has shrunk, just tired of working, or something similar to that? I have an appointment with my GP. I spent a miserable weekend and decided that these gradual symptoms need some investigating.

I am not sure that I can answer your questions because I am not sure that I have all the information. I am assuming that your adrenalectomy was for a cortisol secreting adrenal adenoma. In this situation, the pituitary and the other adrenal are suppressed and depending on how long this had been going on, it can take months to years for the pituitary and adrenal to respond so that you do not need replacement with cortisol or prednisone. This sequence seems to have proceeded in your case.

Your new symptoms are difficult to assess without some lab work. If you are off the prednisone, you should ask your doctor to measure your serum cortisol and ACTH. This will tell you if the other adrenal is working and whether the pituitary gland is functioning normally. If you have this information, it will remove the guesswork so you will know whether you are having a return of your symptoms of Cushing's syndrome or whether there are other causes for your symptoms.

EXERCISE / SPORTS

My 16-year-old son is a very good hockey player, but was recently diagnosed with Addison's disease. He is on replacement with cortisol 30mg daily and Florinef 0.1mg daily. What should he do about his medication when he is playing hockey?

Playing hockey requires extreme energy and response to stress, and there is loss of salt, water and fluid during the game. Players will need extra cortisol (1/2 to 1 tablet), extra salt and water (eg. Gatorade) and possibly an extra 1/2 tablet of Florinef to help retain the salt.

I was wondering about exercise, Addison's and energy levels. I know that if you are "normal" and you exercise, your cortisone increases and your energy in turn increases. What happens when you have Addison's (or no adrenal glands) and you exercise hard? Is your cortisone used up? Does an Addisonian have more energy after exercise (like a normal person)? I have noticed recently that when I have a good workout (e.g. - sweating a lot), that afterwards I feel sick. I try to eat something with a lot of salt, like pretzels, but this nauseated feeling doesn't go

away until much later. So, my question is, if a person who has Addison's exercises hard, should they be taking more cortisone?

If you are going to be doing hard exercise you should take less medication in the morning i.e. Prednisone 4 mg. in the morning and 1 mg. before exercise. (5 mg. Prednisone = 25mg. cortisone acetate = 20 mg. hydrocortisone). Salt and fluids are lost and should be replaced. Be sure you are replenishing fluids, sugar and salt so you are not getting dehydrated. Salt tastes will change according to need i.e. heavy exercise, cross country skiing, in a sweaty hot environment, premenopausal and sweating will also cause water and salt loss.

I have some questions regarding disease management for endurance events. I'm wondering what steps I should take training, leading up to an event, during and after.

I'm 42 and have been athletic all my life (running, skiing or cycling). I was diagnosed in the summer of 2007 with Addison's and have been on Florinef (0.1 mg/day) and Prednisone (5 mg/day) since then. My plans for next year are: a couple duathlons, some 10K races, a 2 days 320K, and a 4 days 800K. My doctor raised the concern that I don't create epinephrine. Is this an issue for me? I've always felt fine on the bike and can approach my anaerobic threshold and hold it there, recover and repeat as I feel is necessary during rides. My heart rate when pushing hard is around 181-185; I have seen it up to over 194 but have been able to recover after it's dropped in a couple minutes.

Currently I routinely ride +/- 100 kms both days on the weekend and shorter rides during the week without issue. Occasionally I feel the need to double up the Prednisone on the second ride of the weekend. Is this the approach I should be using for the multi-day events? And is there a maximum number of days I should be doubling up for?

I admire your stamina and your perseverance. You seem to be doing well on 5 mg prednisone a day for your usual activities. The question is what to do during more strenuous sessions. I am not sure that there is a specific answer to your question of how much steroid you need for these events. My fall back position is that you have to think for your adrenals. If the activity is a little more than usual you may not need more prednisone if you have done this before without incident. If you have not done it before you should play it safe and take an extra 1/2 tablet of prednisone. For more strenuous activities, you should take an extra tablet of prednisone, and if it is going to be a long ride, you may need an extra 1/2 to 1 tablet toward the latter part of the ride. My suggestion for the TFK ride of 200 K per day would be to take either two prednisone at the start, or one prednisone at the start and a second after about four hrs. You may revise your plans after the first day. There is no upper limit on the amount of prednisone each day as long as you do not take it for too long. If you take it for more than week, you should cut back the dose in stages to get back to your usual dose.

You don't have to worry about epinephrine. There are adequate amounts of norepinephrine made at the nerve endings to compensate for any lack of epinephrine from the adrenal.

I've been an Addison's patient for two years now. I take 5 mg Prednisone and .1 mg of Florinef daily. I am an avid cyclist who rides +260 kms per week. These rides are a mix of distance and intensity training. The intensity (interval) training is usually within a few beats of my heart rate max for a minute to two minutes at a time. I've always felt fine after these rides. However, the other day I rode in the morning and saw my endocrinologist in the afternoon and my blood pressure was down to 104/75. My question is, should I be increasing the Prednisone the morning of my rides (I usually ride in the early morning)? If so, by how much? Food intake and hydration is not an issue during or after rides. Depending on temperatures, I will go through ~24 oz of water, with electrolytes, in about an hour to 1.25 hours. I take in about 300 calories an hour to offset what I'm burning.

I admire your weekly program and am envious of your degree of fitness. It seems that the regimen that you are on is quite satisfactory so I don't think that major changes are in order. You mentioned that you are cycling 260+ km /week. You did not mention how many segments you did to make up the 260 km or how long you would be cycling in each segment.

If you cycle on certain days and not on others, then your physical demands on those days would be significantly greater on the days you cycle and you might benefit from an extra 1/2 tablet of prednisone on those days. If you do take extra prednisone, you should take it before you start since it is long acting. If you are doing these in long segments, e.g. 80 – 100 km, then you might require an extra full tablet.

The slightly low blood pressure in the afternoon after a ride could be due to several factors:

- Your pressure may normally run in this range.
- If your pressure is normally higher than this, you may have lost more sodium than you took in. This may depend on the weather and how much you perspire. On hot days, you may want to include some saltier foods to your 300 cal to compensate for salt loss.
- It would be interesting to see if this is a regular finding. You might want to buy a blood pressure cuff to check this out.

I was diagnosed with Addison's in 1995. At that time, my weight was 158lbs., now I'm at 236lbs. I have also been diagnosed with osteoarthritis and find it very difficult to walk. I have joined an aquasize class, but it makes me so tired. Should I be taking extra medication before class and is it normal for my skin to be really dry?

Individuals with Addison's disease do not necessarily gain excess weight when they are on an appropriate dose of cortisol. You did not say what dose of glucocorticoid you are on, but it should be reviewed with your endocrinologist. If you are gaining weight it could be a combination of a) too much glucocorticoid (cortisol, prednisone), b) too many calories and c) not enough activity. I would not suggest that you take extra medication before a normal exercise workout; your normal dose should be enough. Dry skin is not generally a symptom of Addison's disease, and may be a non specific problem. It can be a symptom of an under active thyroid which occurs in about half of the patients with Addison's disease, so this would be worth checking.

I am a recreational soccer player and have just been diagnosed with Addison's Disease. After a very rigorous game last night, I wasn't feeling well. As I came off the field, I felt very cold, which is strange considering I was sweating. Just shortly after that, I started to have vision problems like I was getting a migraine. I had one of my teammates drive me home. My vision returned and the headache started. I have had this happen before during rigorous activity. I am not sure if it is just a migraine, or if I need to be concerned about issues with Addison's?

The episode you describe could have come from several causes. After playing soccer, you may have perspired freely and lost a significant amount of salt. This could have caused a drop in your blood pressure. This frequently results in a "cold sweat". Taking salt-containing drinks such as Gatorade during a game may be helpful. It is also possible that you did not have quite enough hydrocortisone to deal with the stress of a strenuous game. Next time, you might try taking an extra half tablet of hydrocortisone before a game or practice. The third possibility is that it was the start of a migraine. It sounds as if this has happened before in perhaps a slightly different way.

I was diagnosed with Addison's disease in 2004 and celiac the year before. I seem to have a lot of blood sugar crashes. I take 20 mg of cortisol at 6 am and 10 mg at 2pm. I exercise as much as possible and I eat very healthily. This morning, I had my usual breakfast and went snow

shoeing for a half an hour. By time I got home, I was very tired; blood sugar was 3.8. What is wrong?

I am not sure that anything is really wrong. I am not sure what you mean by "crashes". In individuals with diabetes, a crash means a sudden fall in blood sugar. Individuals with Addison's disease can get low blood sugars because they do not have enough cortisol to stimulate the liver to release sugar when it tends to drop below normal.

In your case, you took in your normal breakfast and cortisol and then went snowshoeing for half an hour. If you do not do this every day, you are using more energy and more sugar than usual, so first you are tired and second your blood sugar tends to fall because you have used a lot of it in your activity. Normally, adrenalin and cortisol would stimulate the release of sugar from your liver to replace what you have used up but if you cannot produce more cortisol, this backup mechanism cannot work and your blood sugar might drop below normal.

The best way to avoid problems like this is to think about what you are going to do. If it involves more activity than you usually do, then you should eat a few more calories either before you start or during the activity. You may also need more cortisol depending on how strenuous the activity is and how long it will go on. If in doubt, take an extra half tablet of cortisol and if it goes on for a long time, you may need a full tablet.

You did not mention being on Florinef. This controls the salt levels in your blood. If you do not have adequate levels of salt (sodium) it can make you tired and have low blood pressure. If there is any doubt about this, you should consult your endocrinologist. Most individuals with Addison's disease require Florinef.

FATIGUE

I am newly diagnosed with severe Addison's. My main Addison's symptoms are still chronic fatigue and bodily weakness. I've been on 20mgs/day of Cortef for about a month now. I received about a 40% improvement for my above symptoms, so far. But, I am still very fatigued and unproductive as a result. Should I increase my current 20mgs/day dosage of Cortef or try another drug and dosage instead?

Chronic fatigue and body weakness are non-specific symptoms. It would be helpful to know what investigation was done to make the diagnosis of adrenal insufficiency. If the diagnosis is not correct then cortisol will not solve the problem. If the diagnosis is correct, the treatment usually includes both cortisol and Florinef a hormone that helps with salt retention. The tests to determine if you need Florinef are electrolytes (sodium, potassium and chloride), a test that is readily available, and plasma renin, a test that is available through most commercial laboratories. Twenty mg of cortisol should be sufficient. Remember that Addison's disease comes on over a period of months to years so it may take a while to reverse the changes that have taken place. Before going any further, it is important that you discuss this with your family doctor to review the original diagnosis. If there is no endocrinologist in your area, your family could get a phone consultation from one in a bigger centre.

I have had Addison's for 3 years now. I take 37mg of cortisone acetate and 0.1mg of Florinef. For quite awhile now, I have been getting these feelings of total drain. They can hit any time of day, and in minutes, I feel like a total zombie. There have been times that I have had to leave work to go home to bed. I have had all kinds of tests - B12, thyroid, iron, even for MS. I still have not gained back my muscle strength, although I do exercise every day. I have tried to increase my dosage, add salt to my water, drink more. I'm so frustrated; sometimes I just want to give up. I'm always tired, my personal life is terrible because I just can't think and I have no

energy. I will not give up but keep hoping each day it will get better. I have asked the doctor to check into DHEA which may help? Do you have any suggestions?

I am sorry you are having so much trouble getting your treatment sorted out. I am assuming that this has been going on right from the time of your diagnosis of Addison's disease and, if this is correct, I would want to go back to review the test results that led to the diagnosis. You should review these with your endocrinologist to be sure that there are no other factors that could be causing your symptoms. If the diagnosis is definite, the dose of cortisone of 37.5mg per day, along with the 0.1 mg of Florinef, should make you feel better. These are average doses and adjustments of slightly more or slightly less of each of these medications is usually required. Some individuals feel better if their cortisone is given in 3 doses, and some people find that taking their medication earlier in the day gives them more energy at work. The requirements for cortisone are quite variable and if you are not doing well, measurements of ACTH and renin can be helpful in assessing this. These tests would best be done by your endocrinologist because the interpretation is important. It is also important to remember that a proper diet is important with adequate vegetables and protein and only moderate amounts of carbohydrate to avoid a tendency for reactive low blood sugars 2 to 4 hrs after eating.

I have just recently been diagnosed with Addison's Disease. I am on 20 mg of Cortef and 0.1 mg of Florinef. I am 53 years old and I have a major issue with fatigue. I have been getting mixed messages about my future and fatigue levels. I saw my GP yesterday and discussed Addisons. He advised me that even on medication, I will probably have to live with this level of fatigue. I currently work 4 hrs a day and I am exhausted by the time I get home. Can you give me your advice?

On appropriate medication, your quality of life should be close to normal if other aspects of your health are normal. Your cortisol level may need to be adjusted. Both the dose and the timing of your cortisol are important. We always suggest that the lowest dose of cortisol that makes you feel well is the right dose.

In general, it is best to split the dose to two or three times a day. Examples would be 15mg in the AM and 5mg at lunch. If you seem to be fatigued in the afternoon, you may need a little more cortisol, eg. 15mg AM, 10mg at noon, or 15mg in AM, 5mg at noon and 5mg at supper. The dose of cortisol required can be quite different from person to person so you may need to experiment a little.

The dose of Florinef of 0.1 mg per day should be about right.

I am always tired, whether I get a good rest or not. Is this normal? As well, insomnia is now becoming common. Is this normal?

I know that it seems too simplistic, but it is hard to ignore the connection between your two questions. Insomnia can be related to the timing of taking your hydrocortisone tablets. Some people find that if they take their hydrocortisone in the morning and their second dose in the early afternoon, it does not interfere with their sleep. You can try different times of day for your tablets, and see how it works. Perhaps if you get more sleep, your fatigue will sort itself out. Give it a try and let us know.

FLORINEF / SALT / SODIUM

Please tell me about the Florinef preparation available in Canada.

As you are aware, fludrocortisone is the generic name and Florinef is a trade name. In Canada, Florinef is marketed by Paladin Laboratories. It may be manufactured by BMS, but sometimes these small market drugs are picked up by a small company for marketing. Florinef is the only fludrocortisone preparation available in Canada as far as I am aware. I have not had any experience with generic preparations, but theoretically, the molecule should be the same. You should be able to get information from the pharmacist/chemist where you purchase your medication. They would have the product insert that is available with each drug they sell and they can also get information through web sites on the internet.

I take Florinef. How much should I be taking?

If the dosage of florinef is too low, you may get cramps (due to an imbalance of calcium and magnesium levels). If the level of florinef is too high, you may have high blood pressure. If blood pressure is too high, it is advisable to adjust florinef levels lower before using other medications to lower blood pressure.

Do we Addisonians need to eat more salt than normal?

No - if you are on an appropriate amount of Florinef, a drug with salt retention features, then the salt in a normal diet should be enough. The exception is on hot summer days when you are sweating and losing fluids, you may wish to increase your salt a bit.

I've had Addison's for 6 years now and feel very fatigued most of the time. I'm on a diuretic to lower my blood pressure and I'm consuming huge amounts of salt. I've just switched to Himalayan Salt, which is supposed to be natural and not as harmful as normal table salt. I often feel better after consuming the salt. Is something out of whack with my electrolytes? What tests would answer this question?

One of the problems with Addison's disease is that there is a deficiency of Aldosterone, the hormone that regulates sodium (salt) retention by the kidney. When a diuretic is added in the treatment of high blood pressure, there is additional loss of salt, making it difficult to maintain normal sodium levels in the blood. If sodium levels get low, it can lead to an increased desire to eat more salt. This helps compensate to some degree. Salt is sodium chloride, and is from natural sources. In Canada, it is mined and purified and iodine is added. The iodine is added because the soil in most of Canada is iodine deficient because it is remote from the sea. We need the iodine to make thyroid hormone. Sea salt has iodine in it naturally. I am not sure what additional things might be in salt from the Himalayas. The important component is the sodium chloride which would be the same no matter where the salt came from. The way to assess the status of sodium levels is first to check sodium levels in the blood. These are usually normal, unless there is a severe deficiency. The more sensitive assay is the plasma renin. This would be high if there is sodium deficiency. The renin comes from the kidney and is released in response to a lowering of kidney blood flow. This is relatively easy to measure and this can be arranged by your family doctor or endocrinologist. In general, high blood pressure is more readily treated using a calcium channel blocker such as verapamil rather than a diuretic, because it avoids the problems with salt loss.

I have read that you need to increase Fludrocortisone and salt intake during hot weather. In the summer, I take a lot of hot saunas ranging from 150-180 degrees and then jump into the lake. Do I have to increase my Fludrocortisone and my salt intake on the days I take a sauna? How does this work?

When you are taking your saunas, you are going to be losing salt in your perspiration. You have to replace this by taking in more salt and generally the fludrocortisone that you are taking

will be satisfactory. If you are doing this a lot, you may need to increase both your salt and your fludrocortisone by 1/2 to 1 tablet while this is going on.

I was diagnosed with Addison's about 2 years ago. I am 53 years of age, on about 20mg of hydrocortisone, 0.10 mg of florinef, and 0.088 mg of synthroid. As the nerve endings produce enough adrenalin and noradrenalin to look after the blood pressure needs and the flight and fright response, is it still necessary for me to stay on florinef and if so, why?

This is a good question. There are many factors that are involved in the very complex mechanisms that control blood pressure. Adrenaline and noradrenaline are one of those mechanisms and they have a specific role for specific situations. The adrenal normally produces aldosterone which is involved in the control of sodium (salt) in the body, and sodium in the muscle cells in blood vessels is important in the ability of these cells to contract to maintain our blood pressure. Without adequate sodium in these cells, other factors such as noradrenaline do not have the appropriate effects. The Florinef that you are taking replaces aldosterone. It is a very important part of your adrenal replacement.

I take a diuretic for high blood pressure. Should I adjust my Florinef?

Those on diuretics to reduce blood pressure should consider whether florinef should be decreased. Talk to your endocrinologist about this.

If an Addisonian (primary) is taking extra Fludrocortisone in hot weather, should there be a need to add extra salt? Also, I have been led to believe that postural hypotension in Addison's patients is caused by the low salt and can be rectified by taking extra Fludrocortisone. Is this so, or could the postural hypotension be caused by low prednisone?

Fludrocortisone (Florinef) is a hormone normally secreted by the adrenal gland. It acts on the kidney to increase the amount of sodium that is reabsorbed. Normally, we have lots of salt (sodium chloride) in our diet so taking more fludrocortisone results in an increase in the percentage of sodium retained. If we are perspiring a lot, we may require extra salt so the fludrocortisone will have more to work with.

Postural hypotension is a drop in blood pressure when we stand up. This can be due to several factors. If the blood volume is low, it can be difficult for the muscles around the blood vessels, which help to prevent blood pressure from falling when a person stands up, from maintaining adequate pressure. The fludrocortisone and sodium help to maintain blood volume.

The muscle contraction is stimulated by norepinephrine which comes from nerve endings in muscles. This action of norepinephrine requires the presence of adequate amounts of cortisol or in this case prednisone. Adding excessive amounts of prednisone will not prevent postural hypotension. This requires the correct combination of adequate blood volume and norepinephrine action.

My daughter was diagnosed with Addison's in 2003. She was on Cortef (now on Prednisone 5 mg a day) and Florinef (now fludrocortisone 0.1mg 1 in am and one half in pm). She has had weight gain and thinning skin with the increased dose of fludrocortisone. The "stretch marks" are becoming severe, spreading below the elbows and appearing on her knees, as well as all over her body. We believe her dose is too high but her endocrinologist says no. Is there another medicine that will control the salt balance and keep her blood pressure up without these side effects?

In general, Florinef (fludrocortisone) does not cause symptoms such as stretch marks. Fludrocortisone is responsible for salt retention which in turn affects blood pressure. The best

test to determine if the dose of fludrocortisone is satisfactory is a plasma renin. This is peptide released by the kidney in response to blood pressure and blood flow through the kidney and is very helpful in assessing the dose of fludrocortisone required.

Stretch marks are generally due to thinning of the skin caused by too much glucocorticoid (prednisone or cortisol). The dose requirement for glucocorticoids is variable from one individual to another and studies of cortisol production in non-Addison's individuals has shown that the production can be lower than we previously thought. The best way to avoid stretch marks is to use a short acting glucocorticoid (cortisol) with the smallest dose that allows the individual to feel well. This can be as low as 15 mg of cortisol in some individuals. You should always discuss changes in cortisol doses with your endocrinologist.

I have Addison's Disease. What can happen if I get extremely over heated (hyperthermia)?

Hyperthermia occurs when we are in an environment that is above the normal body temperature. The body generally keeps its temperature down using perspiration which evaporates, using energy, resulting in a cooling effect. If we cannot get rid of enough heat to keep our temperature controlled, body temperature rises resulting in hyperthermia.

This can occur in anyone and is a serious stress to the body. Individuals with Addison's disease are more sensitive to stress because they cannot release cortisol in response to this stress. This type of problem is best avoided. If you are outside, wear clothing that is light in weight and colour, and most important of all, wear a light coloured hat. If you are in a situation where you feel unwell after being in the sun for a prolonged period, you should take an extra cortisol tablet and be sure to get adequate hydration: water is great but you will need some extra **SALT** because you are losing it in your perspiration. It is a good idea to carry a drink such as Gaterade, because it has some salts in it to replace what you are losing. Remember that the Florinef that most individuals with Addison's disease take is for salt retention, and you may have to take a little extra in hot weather and put a little extra salt on your food.

Soft drinks are **NOT** appropriate to replace fluid loss. It is my view that they are not appropriate at any time.

(Ed Note: The July 2008 newsletter included an article on Cooling Vests which will be of interest to Addisonians who suffer from the heat.)

I was diagnosed with Addison's in 2007 and have been experiencing palpitations. I take about 20mg Cortef/daily and take a low dose of Florinef every other day. I believe my palpitations are related to the low sodium/high potassium problem and low blood volume. How can I distinguish exactly which is causing it, the low sodium, high potassium or blood volume? (I've read that they all can cause palpitations). What about hypotremia - is that when I drink too much water?

Palpitations are not a symptom that is particularly common with Addison's disease unless your blood pressure is low and, even then, you are more likely to be light-headed than have palpitations. Your medication dose seems appropriate, and I assume that you have had your blood pressure checked and have had blood tests to measure your sodium and potassium. You should check with your family doctor or endocrinologist to be sure that there are no other factors, such as thyroid problems or anxiety, which could cause palpitations.

HERBAL / VITAMIN SUPPLEMENTS

Can I take an "adrenal support vitamin" from one of the local health food stores, along with my Addison medications?

It is unlikely that this preparation will contain anything harmful with respect to Addison's disease. On the other hand, it is unlikely to contain anything specific that will be beneficial. In adrenal insufficiency, the missing hormones are cortisol and Florinef. There are no specific vitamins that are required. These preparations are usually expensive and do not provide any real health benefit.

Can I substitute my medications with natural products such as herbs?

There are no herb or naturopathic medications that will replace the medications required for treating Addison's disease. Getting the right dose is the important thing.

I have Addison's and I am on 15 mgs of Cortef a day. I am wondering about taking an herbal product called Cold FX that stimulates the immune system, to help with the common cold.

COLD-FX is a specific extract of North American ginseng that is marketed to decrease the frequency and severity of symptoms of the common cold. The available studies have been carried out on healthy volunteers and individuals taking corticosteroids were excluded from the study. This exclusion was most likely designed to exclude individuals taking large doses of steroids as treatment for an underlying disorder and rather than individuals taking physiological doses as is used in Addison's disease. There is however no information about its use in individuals with Addison's disease.

This is a patented over-the-counter medication and the active material and the mechanism of action are unknown. The clinical studies of its beneficial effects are limited. Since the common cold is a self-limiting problem, it is best to avoid potential complications of taking a compound which is not well defined.

Remember, you should increase your hydrocortisone (cortisol) by 1/2 to 1 tablet per day when you have a cold.

I have just been diagnosed with Addison's and I would like to know if I may take glucosamine and chondroitin tablets. I have a bad back and this has helped me in the past.

There should be no problem continuing with the glucosamine and chondroitin sulfate.

Do you know of any reason why anyone with Addison's Disease should not take a vitamin B supplement? I take a multivitamin which has very little B so I increase it with B 50.

There is no problem with taking vit B supplements. I am not sure what is in B50 but as long as it is only B vitamins, it should be OK.

What is the effect of licorice root extract on an Addisonian's immune system?

Raw licorice increases the effectiveness of cortisone; but licorice is not standardized, so strength and quality vary greatly, so you can never really know how much medication the body is getting. Better to leave licorice out of the equation and simply modify the cortisol intake. Because the impact of licorice is on the conversion on cortisone to cortisol, its use would not avoid any unwanted side effects of simply increasing the cortisol medication intake.

Is it safe to take herbal remedies (incl echinacea, ginseng, other immune enhancing products) with my Addison's medications?

Some of these products may change the metabolic breakdown of cortisol, and thus result in a change of the amount of cortisol working in your body. Herbs are not standardized, so the impacts vary on each intake; some may contain licorice which affects conversion; St. John's Wort works on the same enzyme in the liver which converts cortisone; in general, we don't know enough of the contents or action of herbal remedies, so it is suggested that we avoid these unknown variables.

I have read of taking raw adrenal gland pills to rebuild the adrenal glands and taking Tyrosine pills. Is this actually possible?

If you have Addison's disease, it means that your adrenals have been damaged by some process, most commonly an autoimmune process in which antibodies destroy the gland. Other possibilities include infections or hemorrhage. In all of these situations, the gland cannot be "rebuilt". Taking pills containing adrenal tissue obtained from animals will not do anything to improve your own adrenal tissue. Tyrosine is an amino acid which is important, but is readily available in our usual diet. Taking extra will not affect adrenal function.

I was diagnosed with Addison's Disease and hypothyroidism about 6 years ago. I am currently taking Florinef, Cortef and Synthroid. Should I be taking vitamins in addition to the medication, e.g. calcium, vitamin D, vitamin B?

It sounds as if you are doing well on your current medication. There is no specific reason for you to take vitamins if you are eating a healthy diet. There has been a lot published lately about the benefits of vitamin D. Since this vitamin is made in the skin in response to sunlight, it is a good idea to take vitamin D especially in the winter. The recommendation is to take at least 1000 units daily. This dose will just bring your blood levels up to the lower end of normal. Some experts recommend 2000 units. The other vitamins you should be able to get from your diet.

HYPERPIGMENTATION

Do other members still have slightly tanned skin? I feel fine but I still look like I've been on holidays somewhere warm. Not as dark as I once was but I am still tanned.

It is not uncommon for individuals with Addison's disease to maintain an increased pigmentation after they have been treated. It depends on the degree of suppression of ACTH and on the tendency for pigmentation genetically. Someone who has tended to tan easily is more likely to maintain some degree of pigmentation with slightly elevated levels of ACTH. If you are feeling well, I don't think it is a problem from a health standpoint. It may however be a cosmetic problem.

If you want to look into it further, you can get your endocrinologist to measure your ACTH level first thing in the morning before taking your cortisol (it will be high) and then measure it again about two hours after taking your cortisol (it should be quite a bit lower). This will show that your ACTH is responding appropriately to cortisol feedback.

Is it possible to have Addison's without hyper pigmentation? I have been sick for over a year and it has been getting increasingly worse. The doctors are stumped as to what is wrong with me. When I searched online for the symptoms I have, Addison's keeps popping up. I have all the symptoms with the exception of hyper pigmentation. Is it possible I have Addison's or does everyone who gets Addison's have hyper pigmentation?

It is possible to have Addison's disease without the pigmentation particularly in the early stages. The pigmentation does occur in over 90% of cases prior to diagnosis. It is also possible to have adrenal insufficiency on the basis of a pituitary problem. These individuals do not get pigmentation. If you talk to your doctor about this, a blood test for cortisol and ACTH on a morning sample would help to determine whether additional tests would be helpful.

IMMUNIZATION

I have recently been diagnosed with Addison's disease. Should I get a vaccination against the flu?

Individuals have different views about getting the flu vaccine. The fact that you have Addison's should not alter your opinion. If you are on appropriate replacement medication, your immune response to the flu vaccine should be normal and you will get normal protection from this year's brand of the flu. It is important to remember that each year new strains of the flu evolve so your protection will not be absolute but vaccination will reduce your chances of getting the flu.

I'm curious about whether I should be getting the hepatitis immunization shots. From what one of the nurses said, they will not provide hepatitis immunization to anybody who is immunocompromised.

This question that is particularly relevant right now since we are all being asked to get flu shots. The nurses giving the injections have to be sure that the recipient is not allergic to material in the immunization injection, or if they have breathing problems and are using an inhaler, that they have the inhaler with them. Individuals with Addison's disease are not immunocompromised and should respond normally to the hepatitis immunization. The only situation where this may not be true would be if they had a problem requiring larger doses of cortisol or prednisone. If this were the case, they should wait until the problem is over and then go ahead with the immunization once they are back on maintenance doses of their steroids.

What is your opinion on an Addisonian getting the Zostavax vaccine for prevention of shingles? I found out it is a 'live vaccine'; would this be a problem for an Addisonian?

In general, individuals with Addison's disease should have no more problems than the general population in responding to vaccines.

I was told by the Tropical Disease Doctor that anyone taking over 10mg of cortisone should not have a live vaccine as they are apt to present symptoms. This causes problems whenever I want to take cruises or certain trips.

The problem with individuals taking cortisone is difficult to get sorted out. Since individuals with normal adrenal glands secrete between 15 and 30 mg of cortisol daily, there should be no problem with individuals with no adrenal function taking up to 30 mg of cortisol daily. It is my impression that the Tropical Disease doctor meant 10 mg of **prednisone**. This is the preparation used to treat patients who need extra steroids to treat a variety of disorders. Large doses can suppress the immune system, which is why the Tropical Disease doctor was concerned. You should get a note from your endocrinologist or family doctor indicating that the cortisol or cortisone that you are taking is a replacement for non-functioning adrenal glands and is a physiological dose, so there should be no problem.

MENOPAUSE, PREGNANCY, HORMONE REPLACEMENT, BIRTH CONTROL, HYSTERECTOMY

Can a young woman of 17 or 18 take birth control if she has Addison's disease?

Yes. There is no contraindication for individuals with Addison's disease to using the pill. There are however, contraindications to using the birth control pill in the general population that should be respected.

I am pregnant! Do I need to make adjustments in my cortisol or Florinef during pregnancy?

Generally, no. There may need to be adjustments as the pregnancy progresses. This will depend on any symptoms that develop during the pregnancy. However, she will very likely need extra cortisol during the delivery.

My Addison's was diagnosed in 1998 and I am now facing a subtotal hysterectomy and removal of one ovary. Are there problems with combining Hormone Replacement Therapy with Addison's medications? (I also take Synthroid).

There is no problem combining hormone replacement therapy (in this case estrogen alone) with medication for Addison's disease or thyroid medication.

I was diagnosed with Addison's when I was 12 years old. I am now 46. I have been taking Cortef 10mg TID and Florinef 0.1mg "OD" since I was 20. Two years ago I started to show signs of perimenopause. I recently found a book stating a "normal" person would produce extra hormones from the adrenal glands since the ovaries decrease production while going through menopause. My question is how much extra Cortef should I be taking? I have also been having problems with increased BP, is this related to the menopause?

The comment that you heard stating that the adrenal increases its hormone output after menopause is not correct. At menopause, the ovary stops producing estrogen but continues to produce androgens for 1 to 2 years. The adrenal continues with its usual hormone output of cortisol, aldosterone and some weak androgens (DHEA and androstenedione). These weak androgens can be converted to estrogens in fat tissue. The conversion is small -- about 1%, and this contributes to the estrogen production after the menopause. No change in your cortisol dosage is required. The dose of cortisol that you are on is already at the high end of the usual cortisol replacement.

Is it possible to raise your cortisol levels in Addison's by using a certain birth control pill instead of hydrocortisone? I'm a 33 year old female and do not look forward to the side effect profiles presented by the medicines like prednisone, hydrocortisone, etc. Is there a birth control pill that would raise my cortisol levels adequately and present an alternative to hydrocortisone treatment?

You have asked if there is an alternative to taking hydrocortisone for the treatment of Addison's disease. Since the problem in Addison's disease is a deficiency of hydrocortisone, there is no alternative but to replace the hydrocortisone by using hydrocortisone itself or another glucocorticoid. I prefer hydrocortisone. The good news is that you do not have to have bad side effects from the hydrocortisone if the dose is correctly adjusted. By keeping the dose to the lowest dose that makes you feel well, you should be replacing what you need without an excessive dose. This dose would be a total of 15 to 30mg per day in divided doses, generally around 20mg. The birth control pill does not provide any glucocorticoid. In individuals on the birth control pill, the plasma cortisol levels rise to almost twice the normal levels, but this is because there is an increase in the levels of the protein that transports hydrocortisone in the blood. This increased hydrocortisone is not available to get into the tissues so the effective level of hydrocortisone is unchanged.

I am a 53 year old and have had a partial hysterectomy. I have been suffering for the past 6 months or so from severe hot flashes that are really disturbing my sleep, and I am having some of the brain fog that also may go with menopause. It is enough to affect how I can function at work. I have also been diagnosed in the last year with Addison's due to long-term steroid use. My family doctor has suggested HRT for the hot flashes. Is this recommended or even effective with Addison's?

There is no special problem in using hormone replacement therapy in individuals with adrenal insufficiency. Since you have had a hysterectomy, your HRT will be estrogen alone. The studies have shown that women treated with estrogen alone do not have an increased incidence of breast cancer, so this treatment should be relatively safe. I think even with estrogen alone, the rule still stands - the lowest dose for the shortest period to get the outcome you require.

My 18-year-old daughter was diagnosed with Addison's Disease two years ago. Since that time her periods have become very painful. Could this be a coincidence, or is it possible the lack of hormonal stability has contributed to the increased pain? Any suggestions for pain control for her?

Regarding menstrual pain, the pain associated with menstrual periods is due to cramping involved in expelling uterine contents and usually varies from cycle to cycle. This can occur in otherwise healthy individuals.

At the time of diagnosis of Addison's disease the adrenal gland is generally more than 90% destroyed, usually by antibodies directed at one of the proteins in the pathway for cortisol formation. This means that there had been progressive destruction of the adrenal over months to years prior to diagnosis. With treatment, there is a return to more normal cortisol levels.

It is uncertain why your daughter's menstrual periods are more painful now that she is on her medication. It may be a reflection of slightly greater estrogen and progesterone production in a healthier individual resulting in a larger build-up of the uterine lining and heavier menstrual flow. The usual treatment for menstrual cramping is an anti-inflammatory such as Advil, which you can get over the counter, or naproxen or Motrin which are slightly more potent and require prescriptions. These medications are usually very helpful in relieving the cramping.

There is a new form of birth control pill - YASMIN - which is contra-indicated for people with adrenal problems. Why?

Yasmin is a birth control pill that contains an estrogen and a progestational agent as in other birth control pills. The difference is that the progestational component in Yasmin is different from other birth control pills since it also blocks the action of aldosterone, the adrenal hormone that stimulates the kidney to retain salt. This may be a desirable effect in some women because it decreases fluid retention, but in individuals with Addison's disease who are taking Florinef, it will block the salt-retaining effects of the Florinef and could cause a fall in blood pressure. It is therefore not a good choice for women with Addison's disease.

I have had Addison's for over 12 years. I'm thirty, but went into menopause in my early twenties. I don't have children but would like to know if it is at all possible to conceive. I have been told that a donor egg may be a possibility. What are my options?

The answer is yes, it is possible to conceive. But, you would have to see a gynecologist who specializes in fertility problems. The first problem would be to find an egg donor, and there are a variety of factors that should be discussed with your gynecologist about this. The other steps involve preparation of your uterus with appropriate hormone treatment and fertilization of the

donor egg in vitro before placing it into the prepared uterus. Each of these steps require the direction of a gynecologist who specializes in this area. There are many factors involved in this situation and my simplified description may have overlooked some factors in individual cases. These can be covered by your fertility expert.

Is there a relationship in women between hormonal shifts and Addisonian crises? I was first diagnosed at puberty. Shortly after receiving treatment and stabilizing, I started my periods. With my first 2 pregnancies, I had crises during the first trimesters. For my 3rd, we doubled my cortef intake immediately and throughout the pregnancy, and kept out of the hospital. I'm now 44 and often have a 'down' day with Addison-type fatigue just before my period starts. Should I be concerned about how to approach menopause without major glitches?

You have raised some good questions. When you were first treated for Addison's disease at about the time of puberty, you were probably quite unwell. With treatment, your condition would have improved and you then began normal menstruation. Menstrual periods often stop during periods when you are unwell. During pregnancy, the requirement for cortisol increases and the increased requirement is about 1½ to 2 times the regular dose, so you did exactly the right thing. The "down" days prior to menstrual periods are not necessarily related to your Addison's disease and may be due to the changing hormonal production as you approach the menopause. It is not unusual to have some cycles in which you do not ovulate in this situation. With the menopause, I would not anticipate any change in your requirement for cortisol, so your dose for both cortisol and florinef should be about the same.

I recently found out that I am pregnant! Do I need to make adjustments in my cortisol or Florinef during pregnancy?

Generally, no. There may need to be adjustments as the pregnancy progresses. This will depend on any symptoms that develop during the pregnancy. However you will need extra cortisol during the delivery.

I have a pregnant patient who has been very symptomatic with low blood pressure (weak, tired feeling, dizzy, unable to work, etc.). Cortisol studies have been normal. Would she benefit from treatment with Florinef? Is there harm in using this?

There are several changes in adrenal function occurring during normal pregnancy that make tests difficult to interpret. Measurement of urinary free cortisol during pregnancy usually results in levels which are about twice the normal values. This suggests that cortisol secretion increases during normal pregnancy. Progesterone levels rise dramatically during pregnancy and progesterone has interesting effects on both cortisol and aldosterone. First of all it binds to corticosteroid binding globulin (CBG) and displaces cortisol at the same time that estrogen is increasing CBG, so measurement of cortisol in pregnancy is difficult to interpret. Secondly, progesterone blocks some of the mineralocorticoid effects of aldosterone so during pregnancy, aldosterone production increases dramatically. The usual recommendation is to carry on with the usual doses of glucocorticoid and mineralocorticoid during pregnancy but with the physiological changes going on, it is often necessary to make some adjustments. This is particularly relevant if nausea and gastrointestinal problems complicate the situation. The dose of cortisol can be increased stepwise by 5 or 10 mg. to see if it relieves some of the symptoms. The placenta converts cortisol to inactive cortisone so the foetus is protected and will not be affected by these changes. It sounds as if your patient has not required mineralocorticoid replacement prior to the pregnancy. If she is experiencing hypotension, she would probably benefit from Florinef. Measuring electrolytes in the plasma is usually not helpful because these levels only change when things are more advanced. Most individuals with Addison's disease do well during pregnancy on cortisol and fludrocortisone (Florinef) and I am not aware of any concerns with Florinef during pregnancy.

My daughter has Addison's and is pregnant. She is having severe morning sickness. We think. Not sure if the severe vomiting, dizziness, low blood pressure is the pregnancy or Addison's or both. She is 11 weeks and has had to go off work; she is bedridden. Is there anything that she can do? She has doubled her meds. She has been referred to a specialist but that appointment is not till later.

Your daughter did the right thing in increasing her hydrocortisone. She may not need twice as much, just a half tablet extra. With her vomiting, she should have her electrolytes (sodium, potassium, chloride) checked. The other test that would be helpful is a plasma renin. Your family doctor will know what that is. It helps to determine how much Florinef she needs.

Does a body normally produce more cortisone when a female has her period?

Yes - Normally there is a small rise in cortisol just before ovulation. I could not find any literature on whether this should be mimicked in women with Addison's disease.

I was diagnosed with Addison's when I was 12 years old; I am now 46. I have been taking Cortef 10mg TID and Florinef 0.1mg "OD" since I was 20. Two years ago, I started to show signs of perimenopause. I recently found a book stating a "normal" person would produce extra hormones from the adrenal glands since the ovaries decrease production while going through menopause. My question is: how much extra Cortef should I be taking? I have also been having problems with increased BP. Is this related to the menopause?

The comment that you heard stating that the adrenal increases its hormone output after the menopause is not correct. At the menopause, the ovary stops producing estrogen but continues to produce androgens for 1 to 2 years. The adrenal continues with its usual hormone output of cortisol, aldosterone and some weak androgens (DHEA and androstenedione). These weak androgens can be converted to estrogens in fat tissue. The conversion is small - about 1% -, and this contributes to the estrogen production after the menopause. No change in your cortisol dosage is required. The dose of cortisol that you are on is already at the high end of the usual cortisol replacement.

I was diagnosed with Addison's disease 4 months ago. I have been trying to become pregnant for 2 years now. My endocrinologist never indicated a problem with my desire to become pregnant but my family doctor has warned me that in the 2nd and 3rd trimesters there can be complications such as diabetes and pre-term delivery. When looking on the internet, I noticed that Addison's may also put you at higher risk for still birth and congenital birth defects. Can you please give me your thoughts on this? My only other health problem is hypothyroidism.

I hope that you are feeling much better now that you have been diagnosed and are on appropriate replacement therapy. This should include hydrocortisone or cortisone and Florinef.

As you are probably aware, Addison's disease is an autoimmune disease in which antibodies damage the adrenal glands so that they can no longer secrete hydrocortisone or aldosterone. Hypothyroidism is also most commonly an autoimmune process so that these two problems may be related.

Your problem in becoming pregnant for the past few years may have been due to the fact that your general health was not good or possibly something related to your ovarian function. You did not mention whether you were having regular menstrual periods.

If there are no problems with your menstrual periods and you are comfortable with your replacement therapy, there should be no concern about becoming pregnant. Your

hydrocortisone dose may increase a little during the pregnancy, but there is no increase in foetal abnormalities. The pregnancy is likely to go to full-term, and there should be no increase in gestational diabetes unless there are other factors, such as excess weight, which would predispose you to gestational diabetes. Since you have only been on replacement therapy for four months, it may be wise to wait another month or so to be sure you are back to a healthy state.

MISCELLANEOUS

What should be standard lab work for an Addisonian?

- Sodium
- Potassium
- Plasma renin
- TSH (thyroid)
- Fasting glucose
- B12
- TTG antibody to check for celiac, every 5 years

Is there a cure for this disease? Is there a diet that could compensate for the lack of balance in the body originating from the disease?

I am afraid that there is no cure for Addison's disease. It is important to be sure that the diagnosis is correct with the appropriate tests before coming to any final conclusions.

Addison's disease is due to antibodies that are directed to specific proteins involved in the formation of cortisol. Symptoms occur when most of the adrenal has been destroyed by the inflammation caused by these antibodies. Health food stores often carry products that claim to affect adrenal function. These products should be avoided. For someone with true adrenal insufficiency, they are very dangerous.

There has been much discussion about blood donation and organ donation of Addisonians from different parts of the world. Can we as Addisonians in Canada give blood and/or donate organs?

As far as I am aware, there is no restriction regarding these donations. Some Addisonian patients may be anaemic (low hemoglobin) and this may prevent them from donating blood but otherwise there should be no problems

I was diagnosed with Addisons a year ago. I am now in a serious relationship and contemplating sex. I am just wondering if I need more cortisone before having sex?

Having sex should put a little stress on your constitution, but under normal circumstances your usual cortisol dose should be satisfactory. I am not sure what dose of cortisol you are now taking, but if you have any problems once you have assessed the situation, you could always take an extra 1/2 tablet prior to the event.

What is the impact of Addisons on life expectancy?

With proper patient education, there need not be an impact. However, there are implications since Addisonians cannot mount a stress response to things such as pneumonia, infection, etc. If this is controlled, it shouldn't affect life expectancy. If stress is not handled properly, it can

lead to cardiovascular collapse and shock, caused by low blood pressure, caused by insufficient cortisol.

If run-down, fatigued, or ill from a cold or flu, double or triple your cortisone dose for 2-3 days. If you can't keep fluids down, you will need IV medication and fluids from a hospital. Every Addisonian should also have an emergency kit with IM (intramuscular) cortisone.

There is no need to increase Florinef for management of sick days unless suffering from diarrhea. You may need to increase Florinef if sweating profusely (ex. extremely hot weather). Addisonians often take different doses of Florinef depending on whether it is summer or winter.

If undergoing radiation or chemotherapy, you will need to increase your glucocorticoid to deal with both the physical and emotional stress, especially if suffering from nausea.

How will I feel if I have had too much potassium in a day?

In general the body regulates potassium levels in the body and if you take in more than you need, this is excreted in the kidney. Without adequate aldosterone or fludrocortisone, in an individual with Addison's disease potassium levels can go higher than normal and sodium levels go lower than normal. but there are usually no symptoms specific to the elevated potassium. If you took in more potassium than you required in one day, I would not expect you to have any symptoms.

I have spoken to different doctors who say that an Addisonian can consume alcohol like any other person (14-16 drinks per week for males). Other doctors have said Addisonians should not drink at all due to possible pancreas damage etc. Which is true? If the answer is they should not drink, then obviously I would stop, but as my wife and I enjoy wine, I would like to continue to drink a few glasses a week but need to be sure there is no Addisonian risk associated with this.

The problem with individuals with Addison's disease is a lack of hydrocortisone, otherwise they are normal. They should be able to drink normally, such as having a glass of wine with meals or the occasional mixed drink. As with everyone, drinking to excess, or binge drinking can get you into difficulty and in individuals with Addison's disease this could cause a stress you may have difficulty responding to. The short answer is that you can drink in moderation if you have Addison's disease.

How accurate is the salivary testing for steroids and is it available in Canada?

Measurement of salivary steroids has been used with some success, particularly by a group in Wales. It has not received much interest because it is difficult to standardize so I am not aware of any groups that are using this technique in Canada or the U.S.

My 35 year old daughter and her husband live in a small town in BC and have young children 3 and 5 years old. My daughter suffered for about seven months with severe symptoms of Addison's Disease before being finally diagnosed in Dec. 2010. I understand that her town doctor has not had previous experience with this disease. My daughter has been finally been seen by a doctor in the city and is now on replacement hormones. She is now back home but is still very fatigued and not feeling well a lot of the time. I am concerned because she is so far away from major cities where she can get the best help. Can you suggest how she can best receive support? What can be done to help her recover?

It can be difficult when you are far away from your physician, but there are usually ways around it. Your daughter's family doctor has been in contact with an endocrinologists in the city.

She/he can be in telephone contact with one of these specialists for advice. By reviewing the problems with the endocrinologist, her family doctor can make appropriate adjustments and carry out appropriate tests. This information can then be discussed to make any necessary adjustments. I don't think that she should feel so isolated. A good relationship between her family doctor and her endocrinologist can provide her with excellent care.

OSTEOPOROSIS

I have been taking 10mg hydrocortisone for the last 6 years. Lately I have developed osteopenia and feel it may be because of the hydrocortisone. Could this be possible and if so, can you suggest any herbal replacement.

It is always reasonable to ask whether medication that we are taking could be responsible for new problems that come up. I am assuming that you have been diagnosed with adrenal insufficiency and that is why you are taking the hydrocortisone. The adrenal insufficiency can be primary, due to a problem in the adrenal glands, or secondary, due to a problem in the pituitary gland. If the problem is in the adrenal gland, the dose of hydrocortisone (10mg) that you are on, is a relatively low dose and is unlikely to be a factor in your osteopenia. If the problem is in the pituitary, the dose of hydrocortisone is still relatively low and should not cause osteopenia, but there may be other pituitary problems that could contribute to the situation. If you have adrenal insufficiency there are no herbal mediations that you can take that will replace the hydrocortisone. Osteopenia is common in the general population and can be due to multiple factors including diet, activity, age, exposure to the sun (vitamin D) and smoking. The dietary intake of calcium and vitamin D are particularly important. It would be a good idea to review these factors with your family doctor or endocrinologist.

What should I be doing to avoid osteoporosis?

To reduce the risk of osteoporosis, you should take sufficient calcium (1500mg) and vitamin D₃ (recommended dose is now 2000 IU, if vitamin D₃ levels are low, calcium is lost from the bones more quickly). Vitamin K may also be involved. There is information from Japan indicating that vitamin K seems to impact bone density, especially in women. The prescription drug Warfarin reduces the body's vitamin K. Vitamin K is needed for blood clotting.

I have read that the hormone parathyroid has an effect on bone density. Is it true that those with evidence of osteoporosis may find that the reason for this may not lie in the fact that they are long-term steroid users as much as the fact that it may be the parathyroid hormone? Is there any validity to this way of thinking?

There is validity to the possible role of parathyroid hormone in certain types of osteoporosis. Parathyroid hormone is responsible for maintaining blood calcium levels with a narrow range. In cases of calcium deficiency (low intake) or loss of calcium in the urine, parathyroid hormone draws calcium from bone to maintain blood calcium. With adenomas of the parathyroid there is excess parathyroid hormone secreted and this draws calcium from, bone and excretes it in the urine. We encourage individuals to take in 1000mg of Calcium in their diet to deposit calcium in bone and keep the parathyroid levels low to avoid calcium removal from bone. Parathyroid adenomas are uncommon and frequently present with kidney stones. They are a possible cause of osteoporosis in rare situations.

I have read about a new drug called Forteo, a synthetic version of the parathyroid hormone. A recent article in the NEJ of Medicine cited a study of 1637 postmenopausal women, where the bone density had been replenished in just 3 months of treatment to the point where treatment

could be discontinued. So far, it is in the form of self-injected daily shots just under the skin but oral and inhaled versions of it are now under study. Is this "too good to be true"?

There are currently studies underway with the subcutaneous injectible form of this hormone and results are promising. Bone remodeling is a relatively slow process

The doctors of some of our members have suggested that they occasionally go off Fosamax treatments for a while. I have been taking Fosamax for probably 10 years now and have never stopped taking it. What is the reason for going off of it for a while?

Fosamax is an excellent medication for the treatment of osteoporosis. It works by decreasing the normal rate of bone breakdown. The evidence is good that it continues to be beneficial for 7 to 10 yrs, but there is some evidence that some long term users may have an increase in fractures and that these fractures may not heal as quickly as they normally would because the dynamics of bone breakdown and bone formation have been altered. The effects of Fosamax and the other drugs in this family are quite prolonged (years) and this cumulative effect may be responsible for any possible long-term side effects. After taking Fosamax for 10 years, it may be time to consider stopping the medication, so it would be a good time to review this with your endocrinologist.

I was prescribed osteoforte 50,000 IU a number of years ago by my endocrinologist when I started to experience bone loss and was diagnosed as having osteopenia. I also started taking actonel and have been on both ever since, probably 10 years or more. Now with the new knowledge regarding the benefits of vitamin E, I noticed my multivitamin now has 600 IU. Would this not be too much? Is osteoforte the same as vitamin E? Also there have been some new studies regarding calcium supplements contributing to heart disease. Have you heard of this? I usually only end up taking two 300mg tablets a day with magnesium and try to get the rest through food which can be difficult as I don't drink milk.

Osteoforte is vitamin D2, a vitamin D of vegetable origin. It has the same activity as vitamin D3, the kind you make yourself when exposed to the sun. Fifty thousand units is a significant dose, it depends how often you take it. Vitamin D is stored in fat tissue so 50,000 units a month would be reasonable. It would be worthwhile getting your blood level checked. The current recommended dose is 1000 to 2000 units per day.

Vitamin E is a different vitamin. It usually comes in 400 or 800 unit tablets and is not usually involved in bone metabolism.

There has been a small study suggesting that calcium is associated with heart attacks. It is felt that this is not a significant study and no other studies using calcium have shown any similar effect. I think you are quite safe taking two 300mg calcium tablets daily and if you do not eat dairy products, you need this much calcium.

I have been on Actonel for 10 years now due to osteopenia and recently have been hearing some disturbing news about these bisphosphonate supplements. I have had gum recession for years, and now need to have 4 teeth removed due to bone loss and gum recession. The oral surgeon said I would not be a candidate for implants as I am at very high risk of infection due to being on the Actonel for so long. He wondered why I was on it for so long as your body can max out on it after 5 years. I read you should take a break from it and stop it periodically. I also read that it can increase your risk of esophageal cancer. What is a person with Addison's disease supposed to do?

Your question is not related to Addison's disease specifically but really how long should anyone be on a bisphosphonate. I don't think you have done yourself any harm by being on the Actonel

for 10 years. I think however it is time to stop it because you have received the maximum benefit and the material will remain in your bones for a further few years. I don't think your gum recession is related to being on the Actonel.

You should be off the Actonel before any oral surgery; your dentist can give you advice about this but don't let comments such as "your body can max it out after 5 years" upset you because there are a lot of people who have been on these medications for 7 to 10 yrs. The ground rules are still being laid but the recent evidence suggests that now is the time to stop the Actonel. You can get a bone density done in two years to see how things are progressing. Don't be upset about the comments, everything will be fine.

I have been taking hydrocortisone 10 mg for 6 years. Lately, I have developed osteopenia, and I feel it is because of the hydrocortisone. If so, can you suggest any herbal replacement?

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If you have adrenal insufficiency, there are no herbal medications that you can take that will replace the hydrocortisone.

Osteopenia is common in the general population and can be due to multiple factors including diet, activity, age, exposure to the sun (vitamin D), and smoking. The dietary intake of calcium and vitamin D are particularly important. It would be a good idea to review these factors with your family doctor or endocrinologist.

I am a 59-year-old woman with Addison's Disease, taking 20mg hydrocortisone. My bones were fine before; now I have significant osteopenia. Could these meds be the cause?

I doubt if the hydrocortisone at a 20 mg dose would be responsible for significant bone loss. There is commonly a fall in bone density in the early years after the menopause. Are you taking 1000 IU of vitamin D and 1000 to 1500 mg calcium? These are important for bone health.

SECONDARY ADDISON'S

In secondary Addison's, do they replace the ACTH hormone as well as the cortisone therapy?

No, the effect of ACTH is to stimulate the adrenal to make cortisol. Since we are replacing the cortisol, there is theoretically no need for ACTH. To replace ACTH, we would have to inject it either many times per day or daily, depending on the preparation. The tablet approach is felt to be more convenient and more effective.

After several years of being treated for Addison's Disease, I was told by a specialist that it may be Simmonds' Disease. What is that?

Simmonds disease is secondary adrenal insufficiency. This means that the adrenal problem is due to a lack of ACTH from the pituitary rather than a problem in the adrenal gland itself.

I am 62 and I was told I have Addison's. I get a lot of severe headaches and when I bend over or push to go to the bathroom it feels like my head is going to burst. Is this from Addison's because I didn't have this before, and is there any thing I can do?

The symptoms you describe would not normally be seen in individuals with Addison's disease. They seem to occur when you are doing things that increase the pressure in your head. Since I don't know any of the factors leading to your diagnosis, it is hard to speculate on what may be contributing to your symptoms. Individuals who have adrenal insufficiency on the basis of a pituitary problem could theoretically have similar symptoms to those that you describe. Be sure to review your symptoms with your family doctor or endocrinologist.

SHIFT WORK

I'm a 41 yr old male that was diagnosed with Addison's just over a year ago. I take 0.1 mg Florinef and 5 mg of Prednisone each morning. My work requires periodic shift work, where I am required to switch to a 12-8 a.m. time slot for 7 days. What can I do to make this shift easier? I have tried moving the times I take the meds to match my waking hours (on suggestion by doctor). This almost resulted in me having to go to the hospital. Throughout a week of nights, I go through periodic episodes of being quite nauseated. The idea of double dosing for a week doesn't seem right. Is there something more I can do beyond not doing the shift?

Shift work always requires some trial and error to get things right although I think everyone suffers a little when we change shifts. Since cortisol is one of the hormones involved in changing our diurnal changes, Addisonians may actually have an advantage because they can move their cortisol dosing to fit their schedule.

I am assuming that your usual shift is from 8 to 4 or 7 to 3 and the change is to the 12 to 8 shift and the afternoon shift is not a factor. On the day shift, you take your cortisol and Florinef when you wake, eat your breakfast and go to work. I am not sure if you take a second dose of cortisol later in the day. When you are working the 12 to 8 shift, you probably go to bed when you get home at about 9 a.m., and rise at 3 or 4 p.m.

You can try either taking your cortisol and Florinef when you wake up or about an hour before you go to work. The second dose can be taken at the lunch break at work or after you get home. You can see which works best for you both working and sleeping. The days you change over, the doses will be a little closer together or a little farther apart and you can adjust these depending on how you feel.

The key is that you are doing the thinking for your adrenals.

SLEEP

Addisons and sleep disorders?

Addisonians are more likely to have sleep disorders. Addisonians sleep a lot. If you have trouble sleeping, try taking your last dose earlier in the day. Others may take their dose during the night. Those on Dexamethasone may take it late at night as its absorption and metabolism is different than cortef. Play around and find what works best for you.

I was diagnosed with Addison's and am on hydrocortisone, Florinef and also Synthroid as my thyroid stopped functioning as well as the adrenals. I had ovarian failure almost 20 years ago. Is it normal to wake up in early, around 3:30 - 4am and not be able to fall back to sleep for the

rest of the night? This happens frequently since we returned from a trip to Europe. I have taken melatonin for a few weeks and it helped somewhat (I'm no longer taking it), but I now wake up at 5am feeling anxious and worried. I take my hydrocortisone early morning (and Synthroid), noon and at supper time.

The sleep problem is an interesting one and there may be several factors. I am assuming that your sleep pattern was satisfactory before your trip to Europe in August. If that is correct, there would have been a 5hr shift in your body's sleep/wake cycle so that your brain was preparing you to wake up at a new time. When you came home, your body readjusted and this usually takes about a week, depending on how long you were away. This should have sorted itself out by now, but may have been a factor in causing the change. Some individuals on steroid hormones (hydrocortisone, prednisone) have trouble sleeping and this can be helped by the timing of your hydrocortisone medication. You are taking your medication three times a day and this is ideal. By moving the lunch and dinner doses a little earlier, say at 11am and 4pm you may find that this will help with your sleep pattern. You should also review the dose of hydrocortisone because if it is higher than is necessary, this can affect your sleep pattern.

STRESS DOSING

How do I adjust the dosage when responding to stress

If your adrenal glands are not working and you are taking cortisol replacement, you have to do the thinking for your adrenals.

- Minor Febrile illness or stress: Increase glucocorticoid dose 2-3 fold for the few days of illness ("3 x 3 rule"); do not increase florinef; contact physician if illness worsens for more than 3 days. Physical stress such as surgical procedures, a fracture or a major illness will always require extra cortisol. You will always need to administer cortisol prior to any anaesthetic, as the anaesthetic itself is a major stressor. Normally your doctor should look after this but since it is your body never hesitate to ask questions to be sure this has been looked after. Less severe physical stress requires judgment in deciding whether or not more cortisol is required. A headache or a mild sore throat does not normally require added cortisol.
- Emotional stress is less clear-cut since we all respond differently to stress. Regular day-to-day interactions do not require added cortisol, but severe or prolonged emotional stress may require additional cortisol. An extra tablet each day would normally be enough.

One approach used is the "rule of three" = 3 times the dosage for 3 days.

You are best placed to read your own body. You can adjust your cortisol level if you occasionally require it. An extra ½ or full tablet on occasion won't hurt. However, remember that we all "don't feel good" from time to time. This is normal and may not be attributable to your Addison's.

Monitor yourself; think for your adrenals; don't hesitate to increase you dosage if you feel unwell or know you are going into a stressful situation; a little extra won't hurt you from time to time, but don't continue it long term.

What are the risks and benefits of taking extra doses when tired or stressed?

For occasional stress this is OK, very frequent extra doses can cause many side effects, including weight gain, higher blood pressure, osteoporosis and diabetes mellitus.

My grandmother, with whom I have been very close, became ill, was hospitalized and underwent surgery. One month later she died. The whole period was very difficult, I felt unwell throughout. Should I have taken extra cortisol?

During an emotional crisis, an Addisonian must monitor themselves, and may need to increase the cortisol, especially at the moments of highest stress, for example, during the funeral.

I recently experienced an allergic reaction in which I developed a rash, which over a two-day period covered basically my entire body including my face. It was diagnosed as an allergic reaction, likely food or meds related. I asked my dermatologist if I should increase my cortef meds and he didn't think I needed to. It took about 2 weeks to clear up. Should I have increased my Cortef intake at least somewhat during the worst part of reaction to help with the healing?

The circumstances in which you need to increase your cortef depend on the degree of stress that you are experiencing. In the case you describe, the rash was severe enough to cause significant discomfort and it seemed to persist. In this circumstance, it would be appropriate to take an extra tablet of cortef for a few days until things started to settle down and then go back to your regular dose.

I think it is up to you to make the decision about increasing your cortisol dose because only you know the degree of stress you are feeling. It is important that you feel confident in making these decisions because they will usually come up at times when you may not have ready access to your family doctor or your endocrinologist. You will not be creating any difficulties if you err on the side of taking an extra tablet or two. The important thing is that you feel confident in making the decision.

How do we treat illness or surgery?

In someone without Addisons, cortisol secretion increases with the stress of illness and for surgery. So the usual clinical practice is to give higher doses of glucocorticoid to patients with adrenal insufficiency in these situations. Unfortunately, there is little information about how much additional glucocorticoid is needed.

“Doubling Up” during Illness: What does it mean exactly? Ex: If on Hydrocortisone 15 mg in am/5 mg in pm - then increase to 30 mg in am/10 mg in pm. You do not double up on Florinef. **How long to double up for?** Generally 3 days and then back to usual dose; if not improving in 3 days, seek medical help.

What is considered an illness? Cold, flu, gastrointestinal illness.

What about emotional stress? No clear guidelines, but I think it is reasonable if severe stress (death of loved one)

Unusual physical activity? Usually no, but keep up with fluids

Surgery: Mineralocorticoid does not need to be increased during surgery if IV hydrocortisone is used at high doses. I usually omit the Florinef those days because hydrocortisone has some mineralocorticoid activity.

Minor procedures: an extra dose hydrocortisone 25 mg is suggested for the day of procedure; return to the usual replacement dose on the second day.

Moderate surgery: IV/oral doses hydrocortisone 50 to 75 mg are suggested on the day of surgery, and the first post-operative day.

Major surgery: IV 150 mg hydrocortisone for 2-3 days, then return to usual dose or days 2 and 3 use 50% of surgery day.

Chemotherapy and Radiation Therapy - What adjustments, if any, are needed for our medications when we undergo these treatments for cancer? It depends - some chemotherapies have steroid as part of the regimen, so may actually decrease glucocorticoid

dose. Chemotherapy/radiation weaken immune system, therefore, you may be more prone to infections, therefore, I would hesitate to increase glucocorticoids.

I have Addison's disease and currently take 20 mg hydrocortisone daily. I have been nauseated and light-headed lately and my doctor recommended I double up on the hydrocortisone for a week. I was not instructed any further and after the week was up, I went back to the normal 20 mg. I am experiencing anxiety and panic along with upset stomach, so much that daily life is limited. Would this be caused by the sudden decrease in hydrocortisone? Should I have decreased slowly back to the normal amount? What should I do now?

I am assuming that you were feeling well on 20mg of hydrocortisone before your recent problem occurred. I am also assuming that you felt better when you doubled up on your hydrocortisone. I hope that these assumptions are correct. If you felt well on 40mg of hydrocortisone, then it would be wise go back to this dose then to cut it back by 5mg every 2 to 3 days. This would help your body adjust to the change and would help you to know at what dose you felt well. It would also be a good idea to check your dose of Florinef. Your family doctor can do this by measuring your electrolytes and your plasma renin.

What are the symptoms of too much medication?

Symptoms of overdose are the same or similar to the symptoms of insufficient dosage, which is a real problem when fine tuning your dosage. The effects of too high a dose of hydrocortisone include high blood pressure, blood sugar problems (diabetes), increased weight, decreased mental functions; bone density issues/osteoporosis. Symptoms of long-term overdose are similar to the symptoms of Cushings and include weight gain, muscles weakness, bruising, mood change, glucose levels too high.

SURGICAL, MEDICAL, DENTAL PROCEDURES

How do we treat illness or surgery?

In someone without Addisons, cortisol secretion increases with the stress of illness and for surgery. So the usual clinical practice is to give higher doses of glucocorticoid to patients with adrenal insufficiency in these situations. Unfortunately, there is little information about how much additional glucocorticoid is needed.

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dose. Chemotherapy/radiation weaken immune system, therefore, you may be more prone to infections, therefore, I would hesitate to increase glucocorticoids

I need to have my wisdom teeth removed. My dentist is going to do this in the office using general anaesthesia. What should I do about my cortisol?

100mg of Solu-cortef should be administered intravenously before the anaesthetic. The patient should ensure that the dentist is fully aware of her condition and its requirements.

A boy wakes with abdominal pain on the right side of his abdomen – it is diagnosed as appendicitis. The surgeon says that he will be in and out so quickly that he does not need to give the patient extra cortisol. Should you accept the surgeon's opinion?

Any surgery or any general anaesthetic **will** require IV Solu-cortef regardless of the length of surgery. However, too much cortisone can decrease healing, so do not continue "extra" longer than truly needed.

I have secondary Addison's and am wondering about the general protocol for having a colonoscopy prep and procedure? I have heard that people with Addison's may have to spend the night prior to the procedure in the hospital? I also have a high steroid requirement and am on 43.75 - 50 mg. cortisone acetate split over three times per day and various other meds. I've never shown signs of Cushings on this dose other than bone loss but am also on Tegretol and low dose synthroid. I'm also managing a well-controlled seizure disorder. I haven't discussed this with my endocrinologist yet but will soon. Please give me your opinion on this procedure.

Having a colonoscopy is getting to be a fairly common procedure, but that doesn't make it any easier for those going through it. For some people, the prep is more stressful than the colonoscopy itself. It depends on the type of prep. The one involving drinking a large volume of fluid can cause nausea and vomiting and can make it difficult to keep down your cortisone. You should review this with your gastroenterologist. He/she may have a protocol to cover this situation. It depends on the hospital where this is being done. If the prep is going to be done at home, you should take some extra cortisone when you start, in your case, an extra tablet so you would be taking 75mg that day. On the day of the procedure, there are 2 options: to be given 100mg of solucortef intravenously before the procedure; or, to take double your usual dose of cortisone on the morning of the procedure. It also depends on the time of day it is to be done. Usually, it is in the morning and you could request this since it would be easier for you. It would be much less stressful if you were admitted to hospital the day before and you can also discuss this with your gastroenterologist.

All of this should first be discussed with your endocrinologist who can coordinate the procedure with the gastroenterologist. They may have been through this before and have a plan all prepared. An open discussion always makes everyone feel more comfortable.

I recently saw my dentist who suggested that I need to have my wisdom teeth removed. He is going to do this in the office using general anaesthesia. What should I do about my cortisol?

100mg of Solu-cortef should be administered intravenously before the anaesthetic. You should ensure that the dentist is fully aware of your condition and its requirements.

I am having a gastroscopic exam and will be given a light anesthetic. Should I be increasing my 22.5mg of Cortef before this procedure and by how much? I previously had a colonoscopy with a light anesthetic and had to be brought out of the sedation because of a sudden drop in blood pressure. I want to avoid anything like this again.

You should really be discussing this with your family doctor or endocrinologist. It is a general rule that you should take added hydrocortisone during times of stress and there is no doubt that a gastroscopy is stressful. The question is how much more steroid you need for this particular stress. Since you had problems after your colonoscopy, you should take an extra 20mg tablet the morning of the procedure.

Is surgery out of the question for a person with Addison's?

There is no contraindication to surgery in individuals with Addison's disease. They do however require coverage with intravenous glucocorticoids prior to the anaesthetic and during the surgery. The important thing is to be sure that both the anaesthetist and the surgeon are aware that the individual has Addison's disease.

My daughter is in the hospital with appendicitis. The surgeon is going to operate and says that she will be in and out so quickly that she does not need to be given extra cortisol. Should I accept the surgeon's opinion?

Any surgery or any general anaesthetic will require IV Solu-cortef regardless of the length of surgery. However, too much cortisone can decrease healing, so do not continue "extra" longer than truly needed

How do we treat ourselves after we have been discharged from hospital?

If you are admitted to hospital, it usually means that you have some complication such as an infection along with your adrenal insufficiency. While in hospital, you will be given extra cortisol to deal with this stress, and when you go home, you will most likely be on a slightly higher dose of cortisol than your usual daily dose. You will probably be told to stay on this slightly higher dose for a day or so, and when you are back to your usual self, you can go back to your usual dose.

I'm having a colonoscopy. Will the preparation have any impact on my absorption of my medication? How much increase in medication(s) (cortef and florinef) should an Addisonian take? With the last two, I went into severe Addisonian crisis. I take 25mg. of cortef a day. Could this be the extreme laxatives I have to take for the procedure?

Colonoscopies are difficult for everyone, particularly the preparation. The bowel cleanout with the large volume of fluid may well interfere with your absorption of cortef, and since it is a stress, you would need more cortef than normal during the preparation period.

I would suggest that you speak to the individual doing the colonoscopy in advance and explain that you have Addison's disease. Be sure the person who is doing the colonoscopy knows that you have adrenal insufficiency well before the day of the procedure. They may have a protocol for this and that will make the appropriate arrangements. Since you cannot rely on oral absorption of cortisol with the fluid prep, you should have 100mg of solucortef given IV just before the colonoscopy. The most important thing is to be sure that the person doing the procedure knows that you have adrenal insufficiency.

If you are not given any specific instructions, you should take double your usual dose during the prep day before the colonoscopy and take an extra tablet the morning of the colonoscopy. Cortisol is absorbed rapidly when taken orally. The peak blood level is reached in about 30 min so I think you would absorb most of what you take in. It would be a good idea to speak to your family doctor first and ask her/him if they would call the person doing the colonoscopy and make this suggestion. After the procedure, you can go back to your usual dose of cortef.

My 21 year old daughter and was diagnosed with Addison's at the age of eight. Since this time, she has keep in relatively good health but has had several bouts of herpes simplex virus in her eyes which left her with badly scarred corneas leaving her with 7% left in the right eye and 33% in the left eye. She is to receive a cornea transplant. Could you tell me what or if any complications could arise from this?

This is a 21year old female - diagnosed with Addison's disease at age 8 and now has visual problems due to scarring of her corneas from viral infections. The diagnosis at age 8 raises the possibility that she may have a syndrome in which there can be autoimmune involvement of other hormone producing organs and a tendency to have candida (fungal) infections in the mouth and gastrointestinal tract. It is unlikely that this would make her susceptible to the herpes virus infections, but it would be important to be sure there are no other associated problems before corneal surgery. The other autoimmune problems include hypothyroidism, hypoparathyroidism (problems with calcium), pernicious anemia (low hemoglobin), diabetes and vitiligo (patches on the skin with no normal pigment). If everything else is under control the corneal transplants should go well.

My daughter, 19, was diagnosed with Addison's 3 years ago. She is still quite sick and is on several drugs but still suffers with extreme stress. She also has problems with various infections and has trouble recovering from simple cuts and bruises and even from colds and flus. It's as if her whole system is compromised.

My question is whether she should chance surgery for reconstructing her jaw. She has some severe dental problems and the surgeons have suggested 2 operations to break her upper jaw in 3 places and try to bring her impacted teeth into alignment. She is in constant pain with her teeth because of the misalignment.

Has anyone else had surgery such as this and recovered well? The other option would be to try to pull some teeth and try to align the remaining teeth with braces, though it will be harder to fix the problem with braces alone.

Has anyone else noticed extended recovery times after surgery, or being more prone to infections?

The problem with your daughter is a difficult one. First of all, the fact that she has not had a good response to the usual replacement steroids raises concern that there may be other factors going on. I am assuming that she has seen an endocrinologist and her hydrocortisone and florinef replacement are appropriate.

Individuals with Addison's disease generally go through surgery satisfactorily as long as their hydrocortisone coverage is looked after properly, but from what you have said, I am concerned that there may be other things that should be sorted out before considering surgery. Once again, you should discuss this directly with your endocrinologist. The decision about the best procedure in this situation should be reviewed with the oral surgeon. He/she should be aware of your daughter's medical history and the decision can then be designed to fit the situation.

My 8-year-old daughter has Addison's disease. She takes Cortef three times a day by chewing the pills. Her teeth always look like she does not brush them, even though she does, and they have white spots on them. Could this be because of the Cortef?

Before making any comments about the white spots on your daughter's teeth, I would like to hear what her dentist has to say. Since I don't have that option, I will suggest some possibilities, but emphasize that your dentist should see these spots to determine what part of the tooth is involved. My first thought is that in this age group, there is a high incidence of systemic

candidiasis associated with adrenal insufficiency (Addison's disease). This candidiasis is a monilial (fungal) infection that shows up as white spots usually on the tongue and inside of the mouth. It is possible some of this material could appear on the teeth. The fact that she is chewing the cortisone could make her more susceptible to this infection if it is not being washed down well with water after chewing. Children with Addison's disease frequently also have a deficiency of parathyroid hormone (hypoparathyroidism). This can result in defects in the calcification of the teeth as they develop. This can be detected with blood tests for calcium, phosphorous and parathyroid hormone. A third possibility could be too much fluoride. All of these suggestions require the expert advice from your dentist and your endocrinologist.

THYROID

Can lowering your Prednisone and/or Fludrocortisone affect your thyroid levels?

There should not be any effect of changing the dose of these steroids on thyroid levels as long as the doses are in or close to the normal range

Should we take over-the-counter medications that state on the box that they should not be taken if the patient has a thyroid problem.

A manufacturer is obliged to put this warning on the boxes because most of the drugs for allergies or cold remedies contain some type of adrenalin-like compound. If a patient has hyperthyroidism, the combination of excessive amounts of thyroxine plus the adrenalin-like compounds can cause stimulation of the heart. If a person is taking a normal amount of thyroid hormone, there should be no problem in using any of these medications.

My daughter has primary Addison's and type one diabetes. She is experiencing some symptoms of hypothyroidism, yet her TSH is normal. I have read that, because of the cortisone, or Addisons, you can get a normal TSH, when in fact the thyroid is not normal and the only way to really know if the thyroid is working normally is to look at the free T 3 and/or the free T 4.

It is often difficult to differentiate between the symptoms of two chronic diseases – in this case adrenal insufficiency and hypothyroidism. The symptoms of mild hypothyroidism are generally non-specific. Adrenal insufficiency and hypothyroidism can occur together in about 50% of individuals with adrenal insufficiency on an autoimmune basis. They can also occur together in individuals with a pituitary problem. In the autoimmune situation, the pituitary is normal, so the TSH goes up when the T4 and T3 go down. In the situation where the problem is secondary to a pituitary abnormality, the TSH may not be able to go up when the T4 and T3 go down so measuring TSH is not helpful. As you suggested, it is important to measure free T3 and free T4 as well as TSH in these cases. If the adrenal replacement is satisfactory, the thyroid tests should not be interfered with by the adrenal hormones.

I have had Hashimotos thyroiditis for 8 years, and have only been able to get treatment in the past three with Armour thyroid. I have had a lot of trouble getting the dose right, with many periods of hypo. I increased to as much as 6 grains a day and was still hypo. My doctor thought I was probably suffering from thyroid hormone resistance. However, with hormone resistance, the TSH should not be suppressed, and mine was. I did some research on the internet and discovered that my adrenal glands could possibly be insufficient, so we ordered a 24 hour urine test (4X/day) and sure enough, my levels for all 4 were from 0-4 on a range to 20 I believe. I stopped taking thyroid and took only cortef for about 2 weeks, increasing the dose until I felt better. When I started on Armour again, I found I was much better able to tolerate it, with improvement in symptoms that nagged me for years (hair very brittle, severe hair loss, cystic acne, severe dry skin on legs and hands, insomnia...to name a few). My question is this, I

felt better on a dose of 25 - 35mg cortef a day. Then the pharmacy put 10mg tabs in a bottle labeled 5mg. and I took approx 60mg cortef a day for a week before I noticed. I actually felt better, lost weight, hair improved and so forth. I lowered it immediately upon discover to 40mg a day (by the way, I divide my dose 3x/day). I would like to get it lower and then stop eventually when my adrenals appeared to have healed sufficiently. Are these doses all together too high? I have not been diagnosed with Addison's, yet find I'm taking as much or more cortef than those who have. It scares me a little. Also, when I go to have another 24 hour urine test for adrenals, should I take my dose of cortef that day or hold off? Lastly, how can I know it's time to begin to decrease my dosage?

You have posed some interesting but difficult questions. Both your thyroid situation and the adrenal problem are not straight forward. You should be discussing these questions and lab results with your endocrinologist. There are several types of thyroid resistance so even with a suppressed TSH, it would still be a possibility. The Armour thyroid medication contains more T3 than T4 so the blood results can be difficult to interpret if this is not taken into consideration. I am not sure how to interpret you urine cortisol results. If you are going to do more urine cortisol tests you will have to be off medication for at least 48 hrs before starting collection. This is a complex series of problems which needs the expertise of an experienced endocrinologist.

TRAVEL

What should I do when travelling with Addison's disease?

First of all: be sure to have more than enough cortisol tablets with you to cover extra doses of cortisol that you may require if you should get an infection or encounter some other stress. Make sure you have this on you, not in checked baggage. It might also be useful if your travelling companion carries a supply, in case of stolen bags.

Second: take an emergency kit with you. It will help you both practically and psychologically. If you are going to be away for an extended period, you may want to take several kits with you. Be sure one of your travelling companions is familiar with the use of the kit. Your endocrinologist can find these kits on the Canadian Addison Society website (<http://www.addisonsociety.ca/emergencyproc.html>).

Third: Be sure that you have had all the required immunization shots. These should include hepatitis A and B plus tetanus and any specific shots for specific parts of the world.

Fourth: Be sure that you have a letter with you explaining that you have adrenal insufficiency. It should state that you require extra cortisol in stress situations and are carrying cortisol tablets and the emergency kit(s) which contains the solucortef, syringe and needles for emergency use. *(Editor's Note: Sample letters of several kinds and in a variety of languages can be found at <http://www.addisonsociety.ca/emergencylett.html>. Be sure to take emergency procedures and letters in the language of your destination.)*

Fifth: You may want to take some medication to help control diarrhea such as Imodium or Pepto Bismol. You should check this with your family doctor.

I am taking a trip to France. This involves a 6-hour time difference (later). What should I do about my medication?

Maintain the relationship between your medication and the current time of day. So, take your pills before you leave at the usual time and when you reach your destination take your pills at

the same time of day as you did at home. Going eastward, this will increase your overall medication levels slightly but put you quickly onto the correct schedule.

Coming home you will gain 6 hours, so you may need some extra cortisol. Take an extra ½ tablet if you feel that you need it.

What can an Addison patient do about jet lag when travelling across time zones, e.g. a five-hour difference? The person was really ill for five days with flu like symptoms.

When crossing time zones, replacement therapy should be quite simply managed: I advise my patients that they should take their normal doses during the day prior to setting out for a flight. If they are taking 20 milligrams of hydrocortisone on waking as their normal replacement dose, I would then suggest that they take 10 milligrams of hydrocortisone each 6 hours until they reach their destination when they should resume their normal pattern on hydrocortisone replacement according to clock time. If they are on less than this dose in the morning, they should take their normal morning dose 6 hourly in the same way. Fluodrocortisone should simply be taken according to clock time.

I am 42, and have had Addison's disease since I was 16. In the past, I've been treated for food poisoning and other illnesses with a solu-cortef and saline solution. I am soon going to cross the Atlantic with 5 others aboard a 65' sailboat. Would this venture be too risky if I get seasick and my body cannot absorb the cortef? I plan to take injectible Solu-Cortef with me.

A trans-Atlantic trip on a 65' sailboat sounds very exciting. I assume that all of you are experienced sailors and are well prepared for the trip. The fact that you have Addison's disease adds an extra concern, but if you are well prepared you should be able to handle it without too much of a problem. As you know, you should have the Solu-Cortef emergency kits available and each of the members of the crew should be aware of your situation and able to do the injection for you. The Acto-vials come in boxes of 10. I think you should have a box and at least 10 syringes and needles with you. If you should get sick and can't keep your pills down, you will need one and possibly two injections a day depending on the situation. It would also be a good idea to have some drinks along which contain salt, such as Gatoraid.

My husband and I have decided to take a trip to France which would involve a 6-hour time difference (later). What should I do about my medication?

Maintain the relationship between your medication and the current time of day. So, take your pills before you leave at the usual time and when you reach your destination take your pills at the same time of day as you did at home. Going eastward, this will increase your overall medication levels slightly but put you quickly onto the correct schedule. Coming home you will gain 6 hours, so you may need some extra cortisol. Take an extra ½ tablet if you feel that you need it.

A couple of weeks ago, I was informed I have Addison disease. The treatment is hydrocortisone (20mg in the morning and 10 mg at night). I am to travel to Ghana and Nigeria (Africa), and I don't know if it is possible to do this or not, having in mind the medication.

It is certainly possible to travel, even to places such as Ghana, when you have Addison's disease, but you should go over all of the potential problems with your endocrinologist as soon as possible. It depends on how long you will be away, and whether you will have people travelling with you. You should also be familiar with the emergency kit, and your travelling companions should know how to use it. You should discuss your trip in detail with your endocrinologist. You can also get some travel information and information about the emergency kit from the website <http://www.addisonsociety.ca/>.

I've had Addison's for about 20 years. I will be going to Quito, Ecuador next month. The elevation is quite high - around 9200 feet. Do I need to be concerned about altitude illness? I do have a tendency to be lightheaded.

High altitude should not be any more of a problem for someone with Addison's disease than the general population. With the altitude you will get short of breath more easily with exertion due to the fact that the oxygen pressure is less. This is true for everyone. The weather will be warmer, so you will have to be sure you get enough salt in your diet (you may need to add extra). If you are having episodes of light headedness now, you should get your family doctor to check your plasma renin. This is a test to see if you are getting the right amount of Florinef and enough salt. If this is not correct, you may be more susceptible to more light headedness (due to a fall in blood pressure) in hot weather. Addison's disease should not interfere with your trip.

I will be travelling to Mexico shortly. Should I have a letter from my physician to explain at customs why I have to take my medication or is a MedicAlert bracelet sufficient? What should the letter state?

When you are travelling it is always a good idea to have a letter from your doctor which states your diagnosis and the medications that you are on. The pills should be in the bottles that you got from the pharmacy so that they are clearly labeled. When travelling to a place where it may not be easy to get to a doctor, it is a good idea to carry an emergency kit containing solu-cortef and a syringe and needle for injection. This should be clearly labeled. If you are not familiar with the emergency kit, you can get a description from the web site and take it to your doctor.

We required Yellow Fever vaccination for a cruise stop in Columbia, and the doctor would not give me one. I gather that they will not be given to anyone who takes over 10mg of corticosteroids a day. The vaccine is live and complications could result if given. We were told that a waiver would be needed for each trip taken. Is this correct?

This person has raised an interesting question regarding yellow fever vaccination in individuals with Addison's disease. She has stated that her doctor would not give the vaccine to anyone taking over 10mg of corticosteroids per day. I am assuming that this means 10mg of prednisone per day. This would be equivalent to 40mg of cortisol or 50mg of cortisone per day, and this is a slightly higher dose than is normally used for replacement in individuals with adrenal insufficiency. Levels of corticosteroids that are higher than physiological (normal) can suppress the immune system, and can either decrease the antibody response to the vaccine so that the individual will not be protected or can increase the possibility of a reaction to the vaccination. For a full discussion regarding yellow fever vaccination, you can review the Centre for Disease Control web site at [Centre for Disease Control](http://www.cdc.gov). The vaccine is apparently administered at specific approved sites where the physician should have the correct information.

WEIGHT GAIN

I was diagnosed with Addison's about a year ago and have noticed a considerable weight gain. I was taking prednisone until recently, changing to hydrocortisone and florinef about 2 weeks ago. This change has made a big difference and I feel a lot better, but will still need to settle on a dose that will keep me stable throughout my day. However, my weight seems to continue to creep up and my face looks rather puffy. I try to exercise regularly and keep an eye on my diet. If you have any suggestions or comments, I would appreciate it.

The question relates to the dose of glucocorticoid (prednisone or hydrocortisone) replacement. Weight gain and a puffy face are usually symptoms of too much prednisone or hydrocortisone.

The dose of hydrocortisone required may vary from 20 to 40mg per day. It should be spread throughout the day. e.g. 20mg hydrocortisone first thing in the morning, 5mg at lunch and 5mg in the afternoon, or 10mg in the morning, 5mg at lunch and 5mg in the afternoon. The lowest dose that keeps you feeling well is the best for you.

My 16-yr-old daughter was diagnosed with Addison's disease in January after having an Addisonian crisis. She lost a lot of weight at that time but has since gained it back, plus more. Is her body falsely telling her to eat, or is it a side effect of the Cortef, Florinef and Synthroid (for her hypothyroidism)?

When treatment was started, your daughter would have felt better and regained the weight she lost as she was getting ill. Her weight should level out if the dose of cortisol is appropriate. The commonest cause of excessive weight is being on too much glucocorticoid replacement (cortisone, cortisol, prednisone). The lowest dose that makes her feel well is the right dose. This can be as low as 15mg of cortisol a day. The florinef and thyroid are unlikely to be a significant factor in excessive weight gain.

Can I expect weight gain with this disease? I was diagnosed 3 months ago and I am on 15mg of cortef a day and feel pretty good. It has not happened yet, but can I expect it down the road?

Addison's disease is due to a deficiency of adrenal steroid hormones. The treatment is replacement of these missing hormones with hydrocortisone (Cortef) and a mineralocorticoid (Fludrocortisone). If the dose of cortef is appropriate, there should not be a sufficient weight gain. Some people gain weight after being treated because they have lost weight prior to being diagnosed, or because their appetite has improved after being treated. If there is any excessive gain in weight it is most likely due to being on too much hormone. The dose of cortef mentioned is 15mg daily and this is a dose unlikely to cause weight gain.

Why do some people with adrenal insufficiency have weight problems when they are treated with cortisone, while others seem not to have the same difficulty?

The cortisone replacement is designed to return your hormone levels to normal. It is very important that the amount of cortisone replacement is not excessive or it can lead to some weight difficulties. In the past, we have tended to use cortisone or prednisone doses, which may be a little more than are actually needed. In general, patients can get along with either 25 or 37.5 mgs, of cortisone daily or 5 or 7.5 mgs. of prednisone. It's important to balance this with fludrocortisone. We tend to look at ACTH levels and renin levels as a guide to the dose of each of these medications. Once the cortisone and florinef replacement has been appropriately balanced, then activities as well as food intake are both important in maintaining appropriate weight.

Please discuss weight problems. Is the thyroid implicated in weight gain? What about the role of DDAVP?

Since the primary cause of adrenal insufficiency is autoimmune and the primary cause of hypothyroidism is also autoimmune a large proportion of patients with adrenal insufficiency are also on thyroid replacement. The amount of thyroid is titrated to obtain normal levels of TSH and once this has been achieved the patient is generally normal from a thyroid standpoint. In general, if their cortisone, fludrocortisone and thyroxine are at optimum levels, they should be able to maintain their weight as in a normal situation. DDAVP is a hormone that acts on the kidney to control water output and really does not play a role in weight gain or weight loss under normal circumstances.

I am struggling, trying to keep my weight down as I am also diabetic and just starting on insulin. I keep gaining weight. I am on Cortef. What can I do?

I'm assuming you are on Cortef because you have Addison's disease. If you are gaining weight, there are a variety of possibilities:

- You are on more cortisol than you need,
- You are not as active as you should be,
- You are taking in too many calories.

The easiest of these possibilities is the dose requirement for cortisol is variable from one person to another usually between 15 and 30mg per day. The lowest dose that keeps you feeling well is the best for you. Too much cortisol will also make your blood sugar more difficult to control so it is worthwhile taking a careful look at it.