

COMPILATION JUST FOR WOMEN DIAGNOSED WITH ADRENAL DISEASE

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NADF News®, VOL. XXVIII, No. 4 • 2013 Q & A

Q. I was diagnosed with Addison's in 1971. Recently, I underwent surgery to treat breast cancer, followed by radiation treatment. The cancer was luckily caught in stage one. I felt great until they put me on Arimidex. After that, I felt terrible and had every symptom of my Addison's return even though I was on cortisone replacement. They took me off Arimidex, and put me on Tamoxifen. The same thing happened, and I was getting so sick that I went into adrenal crisis multiple times. Is this a known complication of those two drugs?

A. This is not a common event. Arimidex blocks aromatase, which is needed for the production of estrogen. Tamoxifen blocks the estrogen receptor. Neither should have a direct effect on cortisol metabolism. I suspect that the known side effects of these medications, which include aches and pains, might have felt like adrenal insufficiency. The pain itself will cause a need for additional doses of steroids.

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Q. I know woman who had her Cushing's syndrome treated by the removal of one of her adrenal glands, and is hoping to keep the other gland by taking medication. Is it possible for a woman with Cushing's to this extent to become pregnant and carry to full term?

A. The clinical situation is not very clear. If the Cushing's syndrome was due to a benign tumor of one adrenal gland, and that was removed, then the medication would likely be a replacement glucocorticoid such as prednisone taken while waiting for the other suppressed adrenal to return to normal function. If that is the case, pregnancy is possible while still on the prednisone, but will require close monitoring. If, however, the diagnosis is really Cushing's disease due to a pituitary ACTH producing tumor, then the adrenal surgery would not cure the Cushing's and the medication is suppressing adrenal function. In that case, pregnancy would not be feasible because the medication would affect ovarian and placental function.

From NADF News®, VOL. XXVII, No. 3 • 2012 Q & A

Q. I have Addison's Disease. I came off Estrogen 5 months ago. I have been having a lot of trouble with the Addison's since then. Two very close ER visits, low on cortisol all the time. I remember a previous flier from NADF stating that people who are off

Estrogen need more cortisol. It seems true for me. I am thinking of going back on Estrogen because I was so stable then. I took myself off the Estrogen. Is this a common problem with Addisonians? Do you know if most Addisonians go back on Estrogen or take more cortisone?

A. Estrogen increases the amount of a protein (cortisol binding globulin) that carries cortisol in the blood. With increased levels of this protein, there is actually a minor need for higher doses of hydrocortisone to allow a normal free, or active hydrocortisone blood level while on estrogen. That means that if estrogen is withdrawn, free hydrocortisone levels are higher, not lower. In most postmenopausal women these differences are very minor, so adjustments in hydrocortisone dose is usually not necessary. Another effect of estrogen that can be important is the slight salt retaining effect. Withdrawal of estrogen might necessitate a slight increase in need for fludrocortisone to make up for the difference. In any case, with major changes apparently occurring after withdrawal of estrogen, it is a good time to see your endocrinologist to review all medical issues, check for possible changes in thyroid status (this can change with estrogen and can have a major impact on steroid sensitivity) and initiate appropriate changes in hormone dosages.

From NADF News®, VOL. XXVII, No. 1 • 2012

Q. I am a provider with an Addison's patient. She has been doing well on the Hydrocortisone 10mg three tablets daily when she developed hot flashes, mood swings and night sweats. We placed her on a low dose Combipatch and this has alleviated her symptoms however has caused her to blow up secondary to the potentiation of the estrogen on the Hydrocortisone, so we are reducing her Hydrocortisone and expect this edema to resolve.

My questions:

1 Do we have more cases of Addison's then are recognized, as they may present with menopause symptoms and in giving these women HRT, we are increasing the endogenous cortisol levels, thus masking a diagnosis of Addison's?

2 Would repeating the cortisol levels now, with having a baseline, help us to make adjustments to her current dose of steroids?

A. Estrogen does not increase the production of cortisol, it only increases the level of cortisol binding globulin, making the serum cortisol level appear higher. I do not think we are missing patients with adrenal insufficiency. Adding estrogen to a woman with adrenal insufficiency will not relieve the symptoms of adrenal insufficiency, only the vasomotor symptoms. Adjusting for any fluid retention might necessitate a decreased dose of mineralocorticoid, not the glucocorticoid.

From NADF News®, VOL. XXVI, No. 1 • 2011, Q & A

Q. Have any special advice for menopausal adrenal insufficient women dealing with sweats?

A. Treatment for menopausal flushes and sweats remains a problem. The only therapy that works is hormone replacement with estrogen, but this introduces risks, including an increase in breast cancer risk. If the symptoms are severe, a low dosage of hormone replacement may be useful for a short period of time - like 6 to 12 months, using the lowest dose that works, and tapering off slowly (this assumes no current breast or other contraindication). Over the counter remedies are generally plant estrogens that rarely help. Some antidepressant drugs, such as Effexor have been shown to help, but can have side effects, including weight gain. For most women it is best to tough it out. Addisonian women will, indeed, sometimes need a little bit of extra hydrocortisone for stressful episodes, but be careful to avoid taking too much to cover the stress and wind up with weight gain and other features of cortisol excess.

From NADF News®, VOL. XXIV, No. 1 • 2009, Q & A

Q. I think there needs to be some immediate clarification of Dr. Margulies' reply about birth control with Addison's Disease. At least one common birth control pill, Yasmin, CANNOT be used by people with adrenal diseases. This is from the FDA website <http://www.fda.gov/CDER/consumerinfo/druginfo/yasmin.htm>: "Yasmin differs from other birth control pills because it contains a progestin hormone called drospirenone. Drospirenone can increase potassium in your blood. Women should not use Yasmin if they have kidney, liver, or adrenal disease because it can cause serious health problems."

A. Yes, Yasmin as well as the low dose Yaz birth control pills are an exception to the general safety of most birth control pills in Addison's disease. They should not be used.

From NADF News®, VOL. XXIII, No. 4 • 2008, Q & A

Q. I have had Addison's Disease for 7 years now and my current age is 48 years old. I had a question that my doctor can't answer at this time. Can Addison's patient's take birth control pills? I have two large cysts that have grown on my ovaries and the doctor wants to give me birth control pills to receive balanced hormones? Do you know if birth control pills will affect my health since I have Addison's Disease? OR can I take them without out side affects.

A. Yes, birth control pills are safe and effective for women with Addison's disease. They do not have any effect on the dosage of glucocorticoid or mineralocorticoid therapy.

From NADF News®, VOL. XXII, No. 1 • 2007, Q & A

Q. At this time I am actually looking for more information about the safety of the new

vaccine Gardisal® (to prevent HPV infections) and its use in Addisonians. Any help you could provide would be great. Thank you for your time.

A. I think this vaccine is a good idea, and is safe for Addisonians.

From NADF News®, VOL. XXI, No. 3 • 2006, Q & A

Q. Does Addison's disease impact on sexual drive and sexuality?

A. Most people with Addison's disease have perfectly normal libido (sex drive) and sexual function. Men usually have normal erections and ejaculation, and women usually have normal orgasms. When sex drive is lacking, it may be due to sensitivity to the loss of dehydroepiandrosterone (DHEA), measured as DHEAS in blood tests. This is an adrenal androgen, and it is missing because the entire adrenal cortex is lost in Addison's disease. I normally recommend that people with Addison's disease try replacing this hormone with over-the-counter DHEA pills - 25 mg per day for women, 50 mg for men. Sometimes, but not always, this can help. It also may provide a slight sense of improved well being in Addisonians generally. If this does not help, men should have their serum testosterone checked. Also, keep in mind that sexual function can be affected by any other medical problem that might coexist with the Addison's disease, especially thyroid disease and anemia. Other medication can have an effect, such as beta blockers. Finally, don't forget psychological factors. All together, though, there is no reason an Addisonian shouldn't be able to have normal sexual function.

From NADF News®, VOL. XX, No. 1 • 2005, Q & A

Q. I have read that when women are on estrogen and progesterone they need less cortisone, so when they come off estrogen and progesterone wouldn't they need more cortisone?

A. I have not seen any relationship between cortisone dose in Addison's disease and use of estrogen and progesterone.

From NADF News®, VOL. XIX, No. 3 • 2004, Q & A

Q. Could being on hormone therapy (estrogen, testosterone, progesterone) affect the outcome of an ACTH test?

A. The answer to the question is no. None of the gonadal hormones affect the ACTH - adrenal axis, and therefore the standard ACTH stimulation test is not affected. The one exception is the use of Megace, a potent progesterone used to improve appetite in cancer patients. This drug can suppress adrenal production of cortisol.

Q & A's with NADF Medical Director Paul Margulies, MD, FACE, FACP, that have not

yet published in the NADF News®

Q. When a woman with non-classical congenital adrenal hyperplasia nears the age of menopause, is it common to have to alter her dexamethasone dosage, or does the treatment have no effect on menopause?

A. Glucocorticoid treated patients with non-classic CAH will go through menopause at their normal age - usually 48 to 52. Once menses stop, there is no need to stay on glucocorticoid therapy. In fact, many women with non-classic CAH go off glucocorticoids after passing through the child bearing age and switch to birth control pills to maintain normal menstrual function, then stop them at the normal age for menopause. If adrenal androgen production after menopause is significant enough to cause acne or hirsutism, it can be treated with spironolactone, finasteride or Avodart.

Q. I have fibroids and I was wondering what treatments I can take in medications? I have tried BC but they make me sick and I have to take way more cortef. I am scared to have surgery with having Addisons. My uterus is very enlarged and I have ALOT of pain heavy bleeding. They are making me miserable. Will prometrium help?...Thank You for your time

A. Speak to your gynecologist about the choices available for your particular situation. Any of the choices, whether medical or surgical, are compatible with your Addison's disease. If surgery is necessary, a normal steroid cover will get you through it.

Q. Hi there, I am 8 weeks pregnant and have just discovered that my ACTH levels have dropped below normal. My Endocrinologist thought that I would never get into normal ranges again. I have a few concerns about what this means in regards to my steroid meds and being pregnant, but cannot seem to get any answers. Any suggestions?

A. I never monitor ACTH levels in the management of Addison's disease. I treat the clinical signs and symptoms, and I do monitor electrolytes and plasma renin. Depending on the time of day the ACTH level will vary in normal people as well as Addisonians. One possible reason for a lower than expected level may be crossover in the assay from the high levels of HCG coming from the placenta.

Q. Hi, I have Addison's disease and would love to find out if anyone around the world has had the same problems as I during pregnancy. This is my second pregnancy and I seem to have the same problems with my Sodium levels as the first. My sodium is constantly decreasing up to the point when I get incredibly sick and have to get Sodium through IV. My potassium, blood pressure and all other blood values are fine. I am taking 20mg Hydrocortisone and 0.2mg of Fludrocortisone a day. Last pregnancy I had to

spend 2 days in hospital a week and I would love to avoid it this pregnancy. Are you aware of anyone with the same problems? Anyone I can contact about this? My endocrinologist is of no help what so ever. Thanking you in advance.

A. I cannot be definitive about your specific medical situation. Assuming you have only Addison's disease, the most likely answer is that you are not taking enough hydrocortisone. I would definitely have your doctor check you for hypothyroidism, which could contribute to the low sodium. Finally, make sure you are well hydrated, have a normal salt intake (no salt restriction) and avoid purposely over hydrating with large volumes of water.

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