

**Information for Dr. Friedman's Pituitary Surgery Patients
For the Treatment of Cushing's Disease**

PRIOR TO SURGERY

1. Mail back your consent for surgery to Dr. Friedman
2. Write to mail@goodhormonehealth.com with your **name, surgery date**, and your **LOCAL pharmacy phone number**
3. Pick up your hydrocortisone (Cortef) prescriptions before surgery. (Bring your hydrocortisone with you if you are traveling for surgery.)
4. Make sure you have a post-operative blood test requisition for 8 AM Cortisol, ACTH and Electrolytes.
5. Make sure you have an "Emergency" post-op letter.
6. *Write to mail@goodhormonehealth.com to schedule a post-op phone consultation 2 weeks after surgery.*

WHILE IN THE HOSPITAL

The neurosurgeon will manage your pain while you are in-patient and prescribe pain medication at discharge.

AFTER DISCHARGE

1. Withhold your hydrocortisone for 24 hrs and have a blood test the following morning at 8 AM.
2. Dr. Friedman bases your post-op hydrocortisone replacement on many factors, but he often gives 15 mg in the morning and 5 mg at 2 PM. If that is the case, take 15 mg of Cortef IMMEDIATELY after the blood is drawn at 8 AM. After that, take your 5 mg dose at 2 PM and stay on this schedule (15 mg at 8 AM and 5 mg at 2 PM) until Dr. Friedman instructs you to start weaning down. NEVER stop hydrocortisone without discussing it with Dr. Friedman and ALWAYS carry extra hydrocortisone with you.

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- Hypertension and diabetes medications may need to be lowered after surgery. Listen to your body and monitor your BP and sugar. Let your prescribing doctor know, and let Dr. Friedman know, of any significant changes or findings.

WHEN TO SEEK MEDICAL ATTENTION

- ★ Should you experience a sudden loss of function, severe nausea, or vomiting, **IMMEDIATELY** take 40 mg of hydrocortisone. If that doesn't help, give yourself solucortef in an Act-o-vial, 100 mg intramuscular that Dr. Friedman prescribed for you. If you still feel sick and keep vomiting, a, call 911 or go right to the emergency room with the Emergency Letter or remember the following: Hydrocortisone 100 mg IV, Electrolytes check, and IV fluids.
- ★ Should you experience fever or any of the following headaches contact your neurosurgeon: a severe headache that does not allow you to sit up or stand up; headache accompanied by facial pain and dark discharge; headache with a salty tasting drip from the nose or down the back of the throat; a headache accompanied by stiff neck and mental changes.

OTHER

➤ **Common and Expected Post-Op symptoms:**

The following symptoms are expected: aches, headaches, fatigue, dizziness, mild nausea, depression, cold intolerance, irregular sleep patterns, weight changes and frequent urination with increased thirst. *Notify us if the frequent urination and thirst get worse, instead of better, over time.* It is common for women to have unexpected menstrual bleeding shortly after pituitary surgery.

➤ **Headaches are common.**

Headaches are common and expected, especially those that improve with your next dose of hydrocortisone. Some describe these common headaches as, "pressure if I exert," "spike sensations," or "a heavy, wet, sponge in my head." If headaches worsen, it could be a symptom of low sodium, You should get your electrolytes checked and contact Dr. Friedman

➤ **Expect to feel bad.**

Your body was used to abnormally high levels of cortisol. When it leaves your system you will go through withdrawal. Withdrawal from cortisol is no easier than withdrawal from any other substance. Most describe the withdrawal like "the worst flu I ever had in my life." One patient

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wrote, "I feel like hammered dog meat." Please know that this awful period is a good indication that the surgeon got the entire tumor. It is both a good sign and a *temporary* situation.

➤ **Avoid stress.**

After surgery your body is temporarily incapable of managing stress on demand. It is extremely important that you, and those around you, are aware of this and make every effort to reduce stress, expectations and demands.

➤ **Post-op Cortisol**

Dr. Friedman treats many cyclic, mild and/or early cases of Cushing's. Your cortisol number may not drop down and/or stay down in the ranges you read about. Do not be discouraged. Dr. Friedman will assess this data in relation to your particular case.

➤ **Pathology Reports**

Cushing's tumors tend to be tiny and/or loose substances that are easily suctioned during surgery. Many will not get a pathology report identifying an ACTH secretor. This does *not* mean the tumor was missed or that you did *not* have Cushing's. The pathology report can take several weeks to come back. Your neurosurgeon or Dr. Friedman will send you your pathology report if requested.

➤ **Do not take extra hydrocortisone.**

The ONLY time Dr. Friedman wants you to take extra hydrocortisone without consulting him is in the case of severe nausea or vomiting.

➤ **Weaning off the hydrocortisone**

Some patients are eager to reduce their hydrocortisone dose *before* Dr. Friedman recommends. This is not wise. However, since we know patients do this we warn: Never cut by more than 5 mg at a time. Stay on the reduced dose for 4 days before making another cut. Never STOP hydrocortisone without discussing with Dr. Friedman.

FREQUENTLY ASKED QUESTIONS

1. *If my steroids are already too high, why are you giving me steroids after surgery?* Right now you have too much because your tumor makes too much ACTH which leads to too much cortisol. When the tumor comes out you will not have enough. This is because the tumor took over that function from the pituitary gland and, over time, the pituitary just stopped doing it. Post-surgery the tumor is gone and no one is around to tell the adrenals to make cortisol. The

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hydrocortisone replaces what you are not making until such time that the pituitary gland "wakes up" and starts asking your adrenal glands to make cortisol.

2. ***How long will I be in the hospital?*** This varies by surgeon and procedure. With Endoscopic surgery, you may be discharged the next day. Microscopic surgery stays average about four days. Your surgeon is the best person to ask.
3. ***Is Dr. Friedman my Endocrinologist when I am in the hospital?*** The hospital Endocrinologist will manage your case while you are in-patient. We can not let him travel out-of-state to see patients. He will fall too far behind on his email and then we will all be grumpy.
4. ***When should I fly/drive home?*** This varies by patient comfort level and should remain as flexible as possible. Two days after discharge is probably a good plan.
5. ***Do I have to make any special arrangements for traveling home?*** If you are on pain medication you should not drive. We also recommend having a companion who will load/carry all your bags and understand that you will have a difficult time with stressors. A wheelchair to and from the gate at airports is recommended but not required.
6. ***Will Dr. Friedman contact me after my surgery?*** *Dr. Friedman will want to follow-up with you 2 weeks and then 1-2 months after surgery. Write to mail@goodhormonehealth.com to make these arrangements.* He will want to see your post-op cortisol numbers from the hospital, your results after 48 hours without hydrocortisone, and your pathology report if available. Have your surgeon's office (or you) fax the pathology report to: 323-563-9324.
7. ***What happens after surgery?*** You will wean of your hydrocortisone as your adrenal function begins to return. Dr. Friedman will determine when you should have pituitary hormone testing.
8. ***When can I return to work?*** This depends upon your recovery. Each patient is different. We recommend no sooner than six weeks and start with part-time work.
9. ***When will I feel better?*** Some patients report relief of some symptoms immediately after surgery. Some feel worse after surgery. It is possible that psychiatric problems may worsen temporarily after surgery. Some do not report feeling better until a few weeks, or months, after surgery. Often, patients will feel better once they are off the steroid replacement. Some patients become growth hormone deficient following surgery and may not feel better until they are diagnosed and

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treated for growth hormone deficiency. Each patient is different and it can take a long time to feel well after Cushing's. Dr. Friedman strongly advocates patience.

10. *Is there anything else I need to do?* Nope. Just leave your tumor with the surgeon and get well soon!