

Newly Diagnosed with Adrenal Insufficiency/ Addison's? Your Step-by-Step Guide

1. Understanding Your Diagnosis

- **What's happening?** Your adrenal glands aren't producing enough cortisol (and often aldosterone), hormones essential for stress response, blood pressure, and metabolism.
- **Why treatment matters:** Without replacement hormones, symptoms worsen and adrenal crises (life-threatening emergencies) can occur.

2. Immediate Next Steps

✓ Get your emergency kit:

- **Injectable hydrocortisone (Solu-Cortef)** – Learn how to use it *now*.
- **Medical ID bracelet/wallet card** stating “Adrenal Insufficiency – Requires Steroids in Emergencies.”
 - ✓ **Find an endocrinologist** (hormone specialist) for long-term care.

3. Key Blood Tests & Scans (and Why They Matter)

Test/Scan	Purpose
ACTH Stimulation Test	Confirms adrenal insufficiency by measuring cortisol response to synthetic ACTH.
Morning Cortisol	Checks baseline cortisol (low = insufficiency).
Renin & Aldosterone	Assesses salt/fluid balance (often low in Addison's).
Electrolytes (Na/K)	Low sodium/high potassium suggest aldosterone deficiency.

21-Hydroxylase Antibodies	Tests for autoimmune Addison's (most common cause).
Abdominal CT Scan	Looks for adrenal gland damage (e.g., infections, bleeding).

4. Questions for Your Doctor

For your GP/ER doctor:

- “Can you confirm if this is *primary* (Addison's) or *secondary* adrenal insufficiency?”
- “What should I do if I vomit a dose or feel a crisis coming on?”

For your endocrinologist:

- “What's my exact medication plan (doses/timing) for daily and sick days?”
- “How often should I get blood work? Which levels are you monitoring?”
- “Can we create a *written emergency protocol* for hospitals unfamiliar with adrenal crises?”

5. Long-Term Management

- **Daily:** Take meds *on time*, track symptoms/blood work, and never skip doses.
- **Sick Days:** *Double/triple* steroids (per doctor's instructions) – even for a fever or flu.
- **Regular Checks:** Annual tests for related conditions (e.g., thyroid, diabetes).

6. Connect & Advocate

- **Join support groups** (e.g., NADF, Facebook groups).
- **Educate family/friends** on crisis signs (fatigue → collapse = *inject now*).

Key Takeaways:

- **Hormones = Lifesaving.** Missing doses risks crisis.
- **Data is power.** Track symptoms/labs to fine-tune treatment.
- **Prepare for emergencies.** Every. Single. Day.

Print this guide or save it on your phone—your future self will thank you! 