



Managing Adrenal Insufficiency

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Objectives

- Discuss underlying mechanisms of adrenal insufficiency (AI)
- Review signs and symptoms associated with AI
- Discuss 'Sick Day rules' for stress dosing
- Demonstrate how to give intramuscular injection
- Discuss questions or concerns

What is Adrenal Insufficiency?

- Inadequate amounts of one or more adrenal cortex hormones, especially cortisol
- Life threatening condition! Your body cannot maintain essential life functions without these hormones

Permanent

- Addison's Disease
- Congenital Adrenal Hyperplasia(CAH)
- Surgery
 - Removal of pituitary gland
 - Removal of both adrenal glands

Temporary

- Transsphenoidal surgery
- Removal of ectopic tumors
- Medication treatment
- Medical treatment with steroids over a prolonged period of time

Symptoms of Adrenal Insufficiency

Initially

- Unusual tiredness and weakness
- Nausea, Vomiting, Diarrhea
- Loss of appetite
- Stomach Ache

Over-time

- Weight loss
- Darkened skin
- Salt craving



Clinical Features (continued)

Chronic Adrenal Insufficiency

- Fatigue
- Anorexia
- Weight loss
- Myalgia
- Arthralgia
- Nausea
- Vomiting
- Diarrhea
- Orthostatic hypotension
- Salt craving (primary AI only)

Adrenal Crisis

- Severe weakness
- Acute abdominal pain, nausea, vomiting
- Altered sensorium
- Hypotension
- Reduced consciousness

Sick Day Rules

Sick day rules for patients on steroid replacement Hydrocortisone, Dexamethasone, Prednisolone or Prednisone (Glucocorticoid)

Issue/Examples	Patients on hydrocortisone	Patients on dexamethasone, prednisolone or prednisone	Per Health Care Provider
Minor Stress <ul style="list-style-type: none"> Mild cold without fever, Sports (routine physical training/ gym) Psychological stress (i.e. job interview) 	No adjustment	No adjustment	Total dose: ____ mg/day _____ mg morning _____ mg afternoon _____ mg evening
Mild Stress/Illness <ul style="list-style-type: none"> Mild infection, Low grade fever 99.5-101.3°F (37.5-38.5°C), Short time vomiting (once) 	Double your dose during the period of illness	Take _____ mg Hydrocortisone 3x/day in addition to your usual dose of glucocorticoid	Total dose: ____ mg/day _____ mg morning _____ mg afternoon _____ mg evening
Severe Stress/Illness <ul style="list-style-type: none"> Fever \geq 101.3°F (38.5°C), Diarrhea with or without vomiting (but able to keep down tablets) 	Triple your dose during the period of illness	Take 20mg hydrocortisone 3x/day in addition to your usual dose of glucocorticoid	Total dose: ____ mg/day _____ mg morning _____ mg afternoon _____ mg evening

Sick Day Rules

Vomiting – if vomiting occurs wait one half hour to repeat the dose, if cannot keep medication down, inject hydrocortisone

Call your healthcare provider if

- fever/ illness more than 3 days
- any suspected symptoms of adrenal insufficiency
- unable to keep down medication
- whenever hydrocortisone injection is given



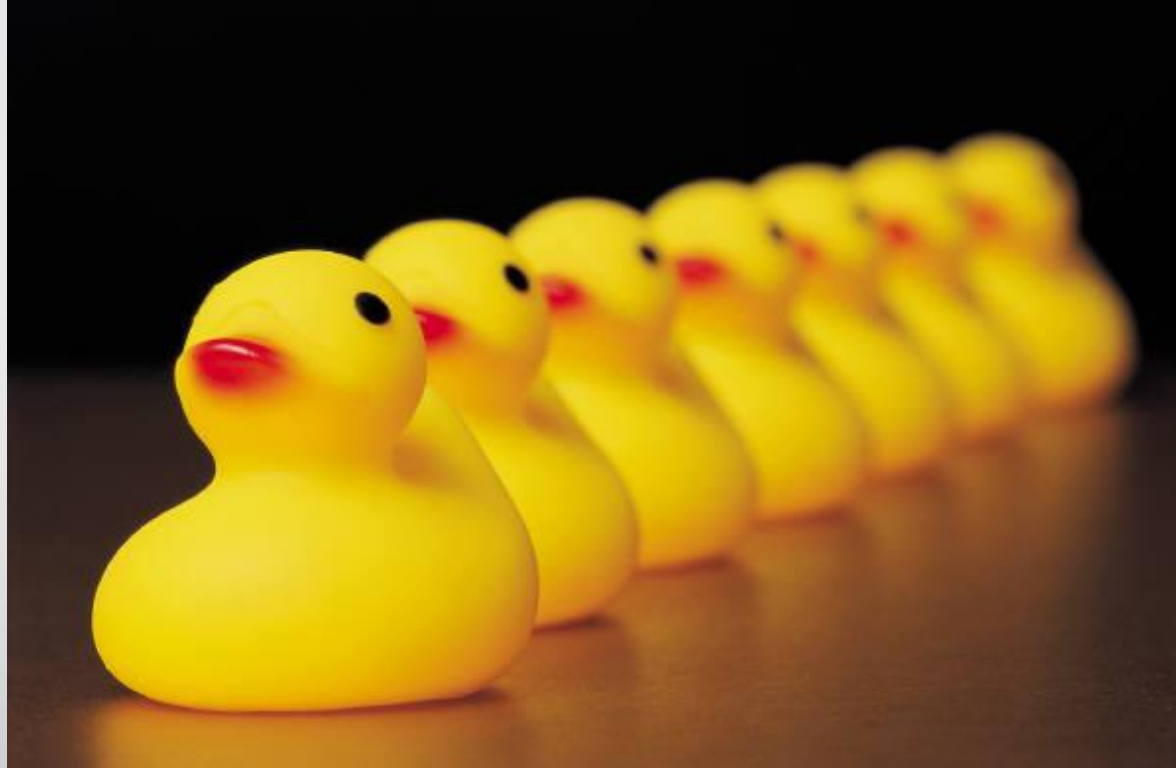
Emergency medical communication

- Medic Alert bracelet or necklace
- "ADRENAL INSUFFICIENCY"- more familiar terminology
- Contact Emergency Medical Services in your area to find out if they can administer Solu-cortef injection
- Focus on: stress dose of hydrocortisone & prevention/treatment of dehydration or hypoglycemia

Daily routine

- Supervise child/ young adult with medication
- Pill box/keychain: keep a day's supply in case you become ill or are delayed getting home
- Smart phone:
 - emergency contact information
 - medication information
 - you-tube video of IM injection
 - photo of sick day rules
- Discuss emergency plan with roommate, spouse, teacher, etc.

Thanks for joining us!



Resources

- Cushing Support and Research Foundation

<https://csrf.net/category/doctors-articles/>

- Adrenal Insufficiency (NIDDK)

<https://www.niddk.nih.gov/health-information/endocrine-diseases/adrenal-insufficiency-addisons-disease>

- Adrenal Insufficiency United

<https://aiunited.org/>

- Magic Foundation
- Adrenal Net
- National Adrenal Diseases Foundation
- CARES (Congenital Adrenal Hyperplasia Research, Education, and Support Foundation)
- Pituitary Foundation



Experiencing Adrenal Insufficiency

Blake Heflin & Shannon Taylor

Adrenal Insufficiency United



Introduction



Our Goals

- Emergency preparedness
- Personal advocacy
- Education and normalization
- Discussion and Questions

Emergency Preparedness

- Personal preparedness
 - Correct documentation
 - Are your medications filled and up-to-date?
 - Prevention
- Educating others
 - Peers, spouses, teachers, employers, etc.

Emergency Preparedness

- Emergency Resources
 - Backpack Health
 - Danny's Dose
 - Sticky J
 - Medical ID jewelry
 - Device apps

Personal Advocacy

- Preparing for appointments
 - Regular documentation of symptoms, experiences, changes
 - Date
 - Did you medicate accordingly? Updose? Stress dose?
- Guiding the conversation
 - Prepared list of your concerns/topics you want to discuss with your physician
 - List in order of importance

Personal Advocacy

- Emergency visits
 - Emergency buddy
 - Inject FIRST, then call 911
 - Effective terminology: “adrenal crisis”
 - More important than specific diagnosis
 - You can NOT sit in the waiting area – you must be seen IMMEDIATELY
- Taking a proactive role
 - Being honest about your needs and your limits
 - Create a team dynamic with your caregivers

Education and Normalization

- Adrenal insufficiency is not always pleasant, but is not always horrible
- Bring AI further into the conversation
 - Importance of sharing stories



Questions