



Autonomic Dysreflexia

Lucas has been waking up every morning at 4 am drenched in sweat. When he turns onto his other side, the sweating goes away and he can go back to sleep again.

Amy gets goose bumps and a pounding headache every time her caregiver does digital stimulation on her bowel program. When the program is done, the headache goes away.

Mitch has had a headache for the past two days that won't go away even after he takes Tylenol or Advil. Also, his muscle spasms have been getting worse and last night he wet the bed – what could be wrong?

What do all of these stories have in common? They all describe typical examples of people experiencing autonomic dysreflexia (AD).

What is Autonomic Dysreflexia?

Autonomic Dysreflexia (AD), also known as autonomic hyperreflexia, is an emergency situation. It is an abnormal response which occurs when your body is experiencing pain or discomfort below the level of your spinal cord injury (SCI). Because the pain or discomfort message does not get to the brain because of the spinal cord injury, the body's blood pressure increases to dangerous levels. If the cause of pain or discomfort is not found and treated immediately, serious complications such as stroke, seizure, organ damage, permanent brain injury, or even death may occur.

Who is at risk for AD?

How susceptible you are to AD is affected by the level and the extent of your spinal cord injury:

- Anyone with a T6 or above level of SCI is at risk
- Individuals with a T6-T10 level of SCI may be at moderate risk
- Individuals with a SCI below T10 are not at risk for experiencing AD

The content in this document is intended for general informational purposes only and is not a substitute for professional medical advice or treatment for specific medical conditions. No professional relationship is implied or otherwise established by reading this document. You should not use this information to diagnose or treat a health problem or disease without consulting with a qualified healthcare provider. Many of the resources referenced are not affiliated with Craig Hospital. Craig Hospital assumes no liability for any third party material or for any action or inaction taken as a result of any content or any suggestions made in this document and should not be relied upon without independent investigation. The information on this page is a public service provided by Craig Hospital and in no way represents a recommendation or endorsement by Craig Hospital.

What happens to your body during AD?

When you are experiencing pain, physical stimulation, or discomfort your body sends a message to your spinal cord which in turn forwards it to your brain. For example, prior to your injury, your bladder would tell your brain, “Hey, getting kind of full down here!” and the brain would direct the body to find a bathroom and then signal the bladder when it was appropriate to go. Now that the spinal cord is injured, the message doesn’t get to the brain and vice versa – your brain just doesn’t know that something is wrong and the bladder keeps expanding with urine - this can be really painful!

Think of AD as the body’s back up plan when the brain doesn’t respond to pain. Because the brain doesn’t get the message of pain, your body makes your blood pressure increase – this is AD. When your blood pressure increases it can cause all sorts of seemingly unrelated signs and symptoms including a pounding headache, sweating, goosebumps, stuffy nose, blurred vision, or red splotchy skin. The increase doesn’t have to be very high to be considered AD, just 20 points above your normal blood pressure in adults and 15 points above normal blood pressure in children.

For example, it’s very common for people to have low blood pressure after spinal cord injury. If your normal blood pressure is 100/75, a signal that you are having AD would be a blood pressure of 120/95—keep in mind, this is considered a normal blood pressure in people *without* a spinal cord injury!

If this is considered normal for most people in the world – why is it so dangerous? Your blood pressure indicates how much pressure your veins and arteries are under every time your heart beats. If your veins and arteries are accustomed to having low pressures and then your heart starts pumping harder and more forcefully, your veins and arteries may not be able to take it. A pressure increase of just 15-20 points above your normal is enough to cause an artery or vein to burst – this is called a stroke and can result in permanent body or brain damage or even death! That’s why it’s so important that you know what your normal blood pressure is and to tell your doctor when it is high for you.

Signs & Symptoms of AD:

- Severe or pounding headache
- Chills or goose bumps
- Sweating
- Changes in vision such as seeing spots or loss of vision
- Anxiety or feeling of apprehension
- Face, neck, or shoulder flushing or splotchy skin
- Nasal congestion
- Slow heart rate

What causes AD?

Anything that can cause pain or discomfort will cause pain and discomfort in someone without full sensation in the body. The three most common causes of AD for people with spinal cord injury are problems with bladder, bowel, and skin.

Autonomic Dysreflexia

Bladder

Bladder problems are the most common cause of AD. The bladder being too full is the first thing to check. Bladder pain or discomfort may be caused by:

- Clogged or kinked catheter
- Catheter bag that is full, is defective, or not attached correctly
- Incomplete emptying of bladder if using intermittent catheterization
- Urinary Tract Infection or UTI - also called a bladder infection
- Bladder or kidney stones
- Sometimes having medical tests on your bladder, like urodynamics or cystoscopy can cause AD

Remember Mitch? He's the guy at the beginning of this handout who had a headache for the past two days that won't go away even after he takes Tylenol or Advil. Also, his muscle spasms have been getting worse and last night he wet the bed – what could be wrong?

Mitch may have a urinary tract infection causing discomfort and irritation in his bladder. Irritation of the bladder is causing him to experience AD and increasing his muscle and bladder spasms (the reason he wet the bed). He needs to go to the doctor and have the infection treated. Once the infection is treated and the bladder is less irritated, his symptoms will go away!

Bowel

Bowel problems can also cause AD. Some common bowel problems are:

- Constipation or hard stools
- Hemorrhoids
- Gas, bloating, or flatulence
- Infection of the bowels

If you recall from the beginning, Amy gets goose bumps and a pounding headache every time her caregiver does digital stimulation during her bowel program. When the program is done, the headache goes away.

Amy is experiencing pain with the digital stimulation that her brain is not registering. Her caregiver needs to be gentler or use more lubricant with the digital stimulation. Or, Amy can talk to her doctor about using a cream that numbs the area.

Skin

Skin issues may also cause AD. Check for the following:

- Pressure sores
- Ingrown toenail
- Burns or sunburns
- Blisters
- Insect bites
- Constrictive clothing, shoes, or braces
- Hard or sharp objects next to your skin
- Incorrect placement or inflation of wheel chair cushion
- Check for constriction of genitalia; rearrange or change your position

Remember Lucas who has been waking up every morning at 4 am drenched in sweat? When he turns onto his other side, the sweating goes away and he can go back to sleep again. Lucas is not turning on a regular schedule and his skin is experiencing pain from too much pressure. When he relieves the pressure and turns onto his other side, the pain is eased and the signs and symptoms of AD go away!

Other Causes of Pain

Keep in mind that anything that caused pain or discomfort before your injury can still cause pain after your injury – but, your brain may not get the message because of the break in your spinal cord. Just because your brain doesn't know about it doesn't mean the pain doesn't exist!

Some things that can cause pain after spinal cord injury that may have a hard time registering in the brain include:

- Abdominal problems such as gallstones, stomach ulcers, gastritis, or appendicitis
- Reproductive problems such as menstruation, infections, and pregnancy (particularly labor and delivery)
- Blood clots
- Heterotopic ossification (HO)
- Broken bones
- Tight or over-stretched muscles
- Severe cold or hot temperatures in the weather

What to do if you have AD

Remember that AD is an emergency situation! Your blood pressure will go up and this is very dangerous. If you're not able to find the cause and treat it immediately, you could have very serious complications such as a stroke, seizure, or damage to your brain, liver, kidney, or heart. All of these are life altering and can result in a brain injury, permanent health problems, or death.

1. If no one is around to help you, **call 911**. If you have help or can do it yourself, you should immediately sit up straight (90 degrees). Do not lie down or recline because this can increase your blood pressure even more.
2. Have your blood pressure checked immediately. You will want to keep the cuff on and have your blood pressure checked every five minutes. Also check your blood pressure after you do any interventions.
3. Next, find the cause and resolve it! Check for skin, bladder, or bowel issues.
 - a. Do you have any skin problems? Loosen any clothing that may be tight such as an abdominal binder, compression stockings, necktie, collars, leg-bag straps, belts, or shoes. Do you have an ingrown toenail? A skin sore? Check your seat – are you sitting on anything hard or uncomfortable?
 - i. If the problem is with the skin and you cannot resolve it – **call 911** and go to the ER immediately!
 - b. Check your bladder - Is your bladder full? Is your catheter kinked or blocked? Are you leaking urine or leaking around the catheter? Make sure urine is flowing freely through the catheter and that your bladder is empty.
 - i. If the problem is with the bladder and you cannot resolve it – **call 911** and go to the ER immediately!
 - c. Do you have bowel problems? Are you constipated? Do you have gas? Diarrhea? Nausea? Vomiting? Quickly do a rectal check for any stool in the rectal vault.
 - i. If the problem is with the bowel and you can't resolve it – **call 911** and go to the ER immediately!
4. If you have checked for bladder, bowel and skin and are unable to stop the AD, **Call 911**. Do not drive yourself as it is dangerous to drive with AD.
5. Also if you have found the cause but are unable to stop AD, **Call 911**.

Don't be surprised if many health care providers don't know about AD. You will have to be a good advocate for yourself and explain what AD is and why it is an emergency situation.

Always carry an AD Wallet Card – this card can be downloaded from the Craig Hospital website. It provides valuable information to your nurses and doctors about AD and how to treat it in an emergency.

Autonomic Dysreflexia

Finally.....

Being a good advocate for yourself means you are an active team player when it comes to your health and the care you receive. If you are not well enough to speak up for yourself, have a friend or family member with you to help direct your care.

- Discuss AD with your family, caregivers, and health professionals so that they are able to help you
- Keep a diary of AD with symptoms, causes, and corrective measures taken
- Call your health care provider and notify them of the episode even if you are able to correct the problem at home
- Keep an AD Emergency Kit with you at all times:
 - Blood pressure cuff
 - Anesthetic/lubricant jelly and gloves (for rectal check)
 - Extra catheter (straight, external, indwelling, or suprapubic) and insertion kit
 - Bladder irrigation kit with normal saline or sterile water
 - Any medications ordered by your doctor to treat AD in emergencies

Remember, you are in partnership with your physician for your long-term health care. You need to tell the doctor what your body can and cannot do. If you don't understand what they are saying or doing or if you are uncomfortable with the plan of care, speak up and ask them to explain it so that you do understand. No questions are out of bounds!