CONSUMER GUIDE: AUTONOMIC DYSREFLEXIA

Paralyzed Veterans of America

consortium for SPINAL CORD MEDICINE
CLINICAL PRACTICE GUIDELINES

SPINAL CORD MEDICINE

Autonomic Dysreflexia: What You Should Know

A Consumer Guide for People with Spinal Cord Injury

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AUTONOMIC DYSREFLEXIA IS A MEDICAL EMERGENCY!

You need to recognize it and get the right care fast!

Autonomic Dysreflexia is a sudden increase in blood pressure, 20 mmHg systolic higher than usual, as a response to something unusual (pain, pressure, unpleasant or pleasant stimulation) happening below the level of injury in persons with a spinal cord injury T6 and above. ***If left untreated, this medical emergency can lead to stroke, seizures, or even death.***

Common Signs & Symptoms

- Sudden increase in systolic blood pressure (top number), more than 20 mmHg
- Pounding Headache
- Sweating
- Flushed or reddened skin
- Goosebumps or tingling sensation
- Blurry vision or seeing spots
- A stuffy nose
- Anxiety or jitters
- Tightness in your chest, flutters in your heart or chest, or trouble breathing

If any of these signs appear, follow the steps below:

1. Sit up or raise your head 90 degrees. IMPORTANT: You need to stay sitting or upright until your blood pressure is normal.
2. Loosen or take off anything tight (abdominal binders, support hose etc.)
3. Check your blood pressure about every 3 minutes.
4. Check for common causes of Autonomic Dysreflexia (bladder, bowel, or skin).
5. If warning signs continue or return, call your healthcare professional, and go to the emergency department.
6. At the emergency department tell the staff you need immediate care:
   - May have Autonomic Dysreflexia
   - Need blood pressure checked
   - Need to remain sitting up
   - Need causes of the problem identified
   - Scan QR code for Clinical Guideline

Note: If your health care professional has given you specific instructions or medications to take if you have Autonomic Dysrefl xia and these are not working, immediately contact your health care professional or emergency department.

Scan QR code for Clinical Practice Guidelines:

Autonomic Dysreflexia: A Medical Emergency

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The information in this Guide is not intended to substitute for prompt professional care. If you develop warning signs of Autonomic Dysreflexia, contact a physician or other appropriate health-care professional as soon as possible.

This Guide has been prepared based on scientific and professional information known about Autonomic Dysreflexia, its causes, and treatment, in 2022. It is recommended that you periodically review this Guide with health-care professionals from whom you regularly receive care.

Administrative and financial support provided by the Paralyzed Veterans of America, Copyright 2022, PARALYZED VETERANS OF AMERICA.

Who Should Read this Guide?

- People with spinal cord injury (SCI) at or above T-6
- Their family, friends, and personal care attendants

Healthcare professionals may obtain a copy of the full Clinical Practice Guidelines at www.pva.org/publications

The higher up your spinal cord injury, the greater chance of developing the serious condition of Autonomic Dysreflexia, often referred to as "AD".

If your injury is below T-6, this guide may still be helpful! People with a lower injury sometimes develop Autonomic Dysreflexia.

Even if you've already learned what to do when experiencing Autonomic Dysreflexia, you may want to keep this Guide handy, for yourself and for people who share in your care.

Be aware, if your level of injury is at T-6 or above, you could also be more likely to experience what is called *silent Autonomic Dysreflexia*. Silent Autonomic Dysreflexia is an episode of Autonomic Dysreflexia where you do not feel or see any symptoms, even when your blood pressure is higher than usual. Talk with your healthcare professional about how you can take your blood pressure at home and keep track of it yourself.

Why is this Guide Important?

Autonomic Dysreflexia can be life-threatening. It requires quick and correct action.

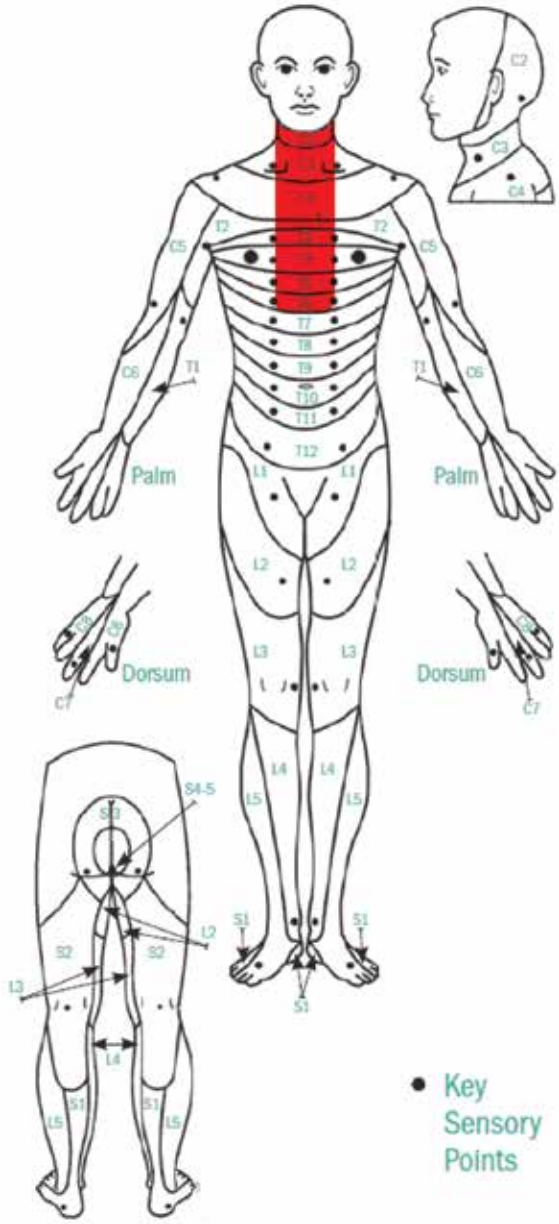
Unfortunately, many health professionals aren't familiar with this condition. That's why it's important for you, and the people close to you, to learn about it. You may have to help guide your own treatment by making sure that healthcare professionals also are thinking about Autonomic Dysreflexia when they are treating you. This is true if you're in an ambulance or at the hospital.

It's a good idea to keep this Guide handy. You may want to have this resource with you at the hospital and share it with the emergency room staff.

Who Gets Autonomic Dysreflexia?

Autonomic Dysreflexia is a condition seen in people with spinal cord injury T6 or above (See Figure A.) If you don't know your level of injury, you can discuss with your healthcare professional.

Figure A:



What is Autonomic Dysreflexia?

1. Something is wrong or different. It could be a pleasant or unpleasant change. There are many possible causes, such as an overfull bladder or bowel. This causes your body to send messages to your spinal cord.
2. Your spinal cord tries to send the messages to your brain. But your injury blocks the message from getting through. (that's why you probably can't feel the pain).
3. The messages to your spinal cord "turn on" special *autonomic nerves.* They make blood vessels in your legs and abdomen squeeze tight and get smaller.
4. This squeezes extra blood into the blood vessels in the rest of your body. The extra blood makes your blood pressure go up suddenly.
5. Sensors near your brain can tell that your blood pressure is getting too high. They try to make your blood pressure go down by sending out three signals:
   a. Signal 1 tells your heart to slow down. (a slow heartbeat is called bradycardia)
   b. Signal 2 goes to blood vessels in your face, neck, and upper chest. It makes them get larger and hold more blood. This can make you look flushed or red and blotchy.
   c. Signal 3 tries to tell the blood vessels in your legs and abdomen to stop squeezing
6. But your spinal cord injury blocks the messages from getting through. Your blood vessels keep squeezing, and your blood pressure stays high. It may even keep rising.

Some Common Causes of Autonomic Dysreflexia

These do not occur in all people with SCI, it is most common in those with injuries at T6 or above or if you have been told by your healthcare professional that you are at risk for experiencing Autonomic Dysreflexia.

Note: Any pain, discomfort, or strong stimulus can cause autonomic dysreflexia!

WHAT CAUSES IT	HOW TO PREVENT IT
BLADDER or KIDNEY	
• Overfull bladder • Bladder problems such as urinary tract infection or bladder infection • If you have a catheter in your bladder and it gets blocked (often from bladder stones) • Kidney stones • Bladder tests, treatments, or surgery, such as cystoscopy and urodynamic tests	• Follow a reliable bladder management routine. If you catheterize yourself, keep your bladder from getting too full. If you have a catheter, keep your drainage bag from getting more than half full and check to make sure the catheter is not blocked. • Have checkups (often done yearly) that include bladder tests. Ask if your health-care professionals have experience with Autonomic Dysreflexia. Share this information and plan with them beforehand.
BOWEL* OR ABDOMEN	
• Bowels that are getting too full (constipation) • Problems such as gallstones, stomach ulcer or gastritis, hemorrhoids, anal fissures, or appendicitis • Bowel or abdominal tests or surgery, such as sigmoidoscopy or barium enema • Stick to your bowel program to prevent constipation or bowel accidents. If constipation is a problem, you may need to change your bowel program.	• Work with your health-care professional to determine your usual fiber intake. Any increase in fiber intake should be done gradually, from a wide variety of sources, and be monitored by a health-care professional. • Drink plenty of fluids. Ask your health-care professional about the right amount for you and your bladder program. • Checkups (often done yearly) may include bowel tests. Ask if your health-care professionals have experience with Autonomic Dysreflexia. Share this information and plan with them beforehand.

* For more detailed information on bowel care, a complete bowel management clinical practice guideline is available at the website: www.pva.org/publications

Call your healthcare professional if you are having a lot of constipation or bowel accidents.

WHAT CAUSES IT	HOW TO PREVENT IT
SKIN	
• Laying on, touching, or cleaning a pressure sore (pressure ulcer) • Other skin problems that would cause pain if you had feeling, such as ingrown toenails, burns (including sun burns), skin rash or infection, or insect bites • Something hard or sharp pressing on your skin	• Check your skin at least once a day for red spots, scrapes, or scratches below your SCI. If you find any, call your health-care professional right away. • Try to avoid situations where you're likely to get burns, cuts, scrapes, or other injuries. • Keep sharp or harmful things out of your bed and wheelchair. • Make sure your clothes, shoes, appliances, and braces fit comfortably. Be especially careful if they're new.
SEXUAL ACTIVITY OR REPRODUCTION	
• Too much penile or clitoral stimulation, especially using a vibrator • Men: ejaculation, infection, or inflammation of the testicles (epididymitis), or pressing or squeezing of the testicles • Women: orgasm, tampon insertion, menstruation, pregnancy (especially labor and delivery), infections of the vagina (vaginitis) or uterus (pelvic inflammatory disease), and breastfeeding (sometimes)	• Be aware that these activities and conditions are possible causes of Autonomic Dysreflexia. Stop what you are doing and sit up if you think you are experiencing Autonomic Dysreflexia. • Talk to your healthcare professional about these possible causes. • If you're pregnant or planning a pregnancy, look for an obstetrician/gynecologist who's willing to work with you and with other health-care professionals who know your SCI care.
SOME OTHER CAUSES	
• Blood clots in the leg or pelvis veins • Deep Vein Thrombosis that may travel to the lungs (pulmonary emboli) • Broken bones or other injuries • Everyday problems such as too-tight clothing, tight abdominal binders, shoes, appliances, or braces • Extreme temperatures (too hot or too cold), or quick temperature changes • Some medications that increase blood pressure (such as midodrine)	• Recognize that all these problems can cause Autonomic Dysreflexia. Alert your health-care professionals and share this information with them. • Make sure your clothes, shoes, appliances, and braces fit comfortably. • Try to avoid extremes in temperature. Plan to dress appropriately. • Loosen your abdominal binder if you start to experience Autonomic Dysreflexia • Talk to your healthcare professional about holding off on medications that increase your blood pressure if you start to have symptoms of Autonomic Dysreflexia, are undergoing bladder testing, or have a medical problem such as a UTI.

For more detailed information on Deep Vein Thrombosis (Thromboembolism), a clinical practice guideline: *Prevention of Venous Thromboembolism*, or a Consumer Guide: *Blood Clots. What You Should Know* are both available at the website: www.pva.org/publications

What Are the More Common Warning Signs of Autonomic Dysreflexia?

While many people may experience one or more of the signs or symptoms below, many people may not have any signs or symptoms when experiencing Autonomic Dysreflexia.

The most dangerous sign of Autonomic Dysreflexia is a sudden, major increase in your blood pressure. A major increase is an increase of at least 20 mmHg higher than your usual systolic blood pressure, which is the top number in your blood pressure reading.

Your baseline or resting blood pressure may vary, so it is important to know your normal blood pressure.

Even though there may be other signs or symptoms of Autonomic Dysreflexia, be aware and sensitive to those listed below, as they are often the most common warning signs of Autonomic Dysreflexia:

Autonomic Dysreflexia Common Warning Signs:

- A sudden increase in systolic blood pressure (top number) more than 20 mm Hg
- A pounding headache
- Sweating
- Flushed or reddened skin
- Goosebumps or tingling sensation
- Blurry vision or seeing spots
- A stuffy nose
- Anxiety or jitters
- Tightness in your chest, flutters in your heart or chest, or trouble breathing

If I think I have Autonomic Dysreflexia, what should I do?

Prompt action is essential! If you need assistance with any of these steps, ask someone to help you. It's important to do the steps in the order listed below:

Important: You need to remain sitting or upright until your blood pressure is back to normal. Lying down may make your blood pressure go higher.

Step 1: Sit up or raise your head to 90 degrees. IMPORTANT: You need to stay sitting or upright until your blood pressure is normal.

Step 2: Loosen or take off anything tight (clothes, abdominal binders, support hose etc.)

Step 3: Check your blood pressure about every 3 minutes.

Step 4: Check for common causes of Autonomic Dysreflexia (bladder, bowel, or skin).

Step 5: If warning signs continue or return, call your healthcare professional, and go to the emergency room.

Step 6: At the emergency department tell the staff you need immediate care:

- May have Autonomic Dysreflexia
- Need blood pressure checked
- Need to remain sitting up
- Need causes of the problem found or identified
- Scan QR code for Clinical Practice Guideline

Step 7: Follow-up with your healthcare professional, **even if warning signs went away.**

QR Code for Autonomic Dysreflexia Clinical Practice Guidelines:

Talk About It!

Discuss Autonomic Dysreflexia with your family, personal care attendants, and others who share in your care. They need to know how to recognize it and help you if it occurs. And don't forget to bring up this subject with your healthcare professionals!

If you're having tests, surgery, or a baby, make sure your healthcare professionals are ready to monitor and manage Autonomic Dysreflexia, if it develops.

What Goes in an Autonomic Dysreflexia Kit?

Even when you are doing all you can to prevent AD, it can still happen. That's why it's a good idea to make an Autonomic Dysreflexia kit, and always keep it with you. Here's what it should contain:

A blood pressure cuff

This can be a wrist or arm style. Make sure that you, your family, and attendants know how to use it.

A catheter and supplies

Any medications that your healthcare professional prescribed for Autonomic Dysreflexia

Check their expiration dates and keep fresh supplies in your kit.

A copy of this Guide

Be sure to discuss your Autonomic Dysreflexia kit with your healthcare professional. Ask if you should include other supplies. Also ask if your healthcare professional can give you prescription items for your kit.

My Personal Autonomic Dysreflexia Diary

This personal diary is intended for you to use to keep a record of your Autonomic Dysreflexia episodes. Keep this Diary and the Guide with you.

Date of Autonomic Dysreflexia Episode: _____

My baseline blood pressure is typically: _____

My highest blood pressure during this Episode was: _____

Symptom List:
Put a checkmark or "X" next to every symptom you had during your Autonomic Dysrefl xia episode. Record the severity on a scale of 1-10, with 10 being the most severe. Also list the duration of each symptom in minutes.

- ☐ Pounding Headache
- ☐ Stuffy Nose
- ☐ Heavy Sweating
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Cause of Autonomic Dysreflexia episode, treatment, and response. Provide time from beginning of episode until the end.

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