

**MEDICAL
EMERGENCY**

AUTONOMIC DYSREFLEXIA: WHAT YOU SHOULD KNOW



Consortium for Spinal Cord Medicine

Administrative and financial support provided by Paralyzed Veterans of America

What to Do If You Think You Have Autonomic Dysreflexia:

Prompt action is essential! If you can't follow these steps yourself, tell a family member, an attendant, or a friend what to do. It's important to do these steps in the order below.

1. Sit up, or raise your head to 90 degrees. If you can lower your legs, do.

Important: You need to stay sitting or upright until your blood pressure is back to normal.

2. Loosen or take off anything tight:
 - External catheter tape
 - Abdominal binders
 - Clothes
 - Shoes or leg braces
 - Elastic hose or bandages
 - Leg bag straps
3. If you have a blood pressure kit, take your blood pressure reading about every 5 minutes to see if you're getting better.
4. Check to see if your bladder is draining properly (see page 4, step 4).
5. Call your health-care professional, even if the warning signs go away. Report the symptoms you had and what you did to correct the problem.
6. If the warning signs come back again, repeat these steps. Even if the warning signs go away again, call your health-care professional and go to the emergency room.
7. At the emergency room, make sure you:
 - Tell the emergency room staff that you think you may have autonomic dysreflexia and need immediate treatment.
 - Ask to have your blood pressure checked immediately.
 - Request to keep sitting up as long as your blood pressure is high.
 - Ask the emergency room staff to look for causes of the problem. Suggest that they check for causes in this order: (1) bladder, (2) bowel, and (3) other causes.
 - Suggest that your health-care professional instill anesthetic jelly into your rectum before checking your bowel.

Important: Inform the emergency room staff that there is a complete clinical practice guideline available at the website: www.pva.org.

AUTONOMIC DYSREFLEXIA: WHAT YOU SHOULD KNOW

A Guide for People with Spinal Cord Injury

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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 1997. It is recommended that you periodically review this Guide with health-care professionals from whom you regularly receive care.

Acknowledgments

The Consortium for Spinal Cord Medicine for development of clinical practice guidelines is composed of 17 organizations interested in spinal cord injury care and treatment. The Consortium Steering Committee established a guideline development panel to make recommendations on how best to prevent and treat autonomic dysreflexia because of its life-threatening nature. The consumer panel was chaired by Todd A. Linsenmeyer, M.D., and consisted of nine members with experience in autonomic dysreflexia from varying health care professions. The recommendations are based on the world-wide research information available on the topic. The panel was assisted by an expert team from the University of North Carolina at Chapel Hill who reviewed the literature and determined the quality of the research. The Paralyzed Veterans of America provided financial support and administrative resources for all aspects of guideline and consumer guide development.

The guideline development process leads to professional agreement on a topic. After the panel writes their guideline recommendations, many outstanding clinical and scientific experts review the draft guideline. The panel accepts or rejects the reviewers' opinions by voting and prepares the final guideline for legal review and editing. In the development of consumer guides, a consumer focus group of six or more spinal cord injured individuals reviews the guide with the panel to make it more readable and easy to understand.

The Consortium for Spinal Cord Medicine is appreciative of the fine work of the guideline development panel, the expert field reviewers, and the writers, editors, and consultants that contributed to the content and quality. In particular, the Consortium would like to recognize the outstanding contribution by the American Association of Spinal Cord Injury Nurses (AASCIN) in providing their consumer and family education material.

The Consortium will continue to develop clinical practice guidelines and consumer guides on topics in spinal cord injury care. Look for consumer guides on other topics in spinal cord injury.

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- American Association of Neurological Surgeons
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- American Association of Spinal Cord Injury Psychologists and Social Workers
- American Congress of Rehabilitation Medicine
- American Occupational Therapy Association
- American Paraplegia Society
- American Physical Therapy Association
- American Psychological Association
- American Spinal Injury Association
- Association of Academic Physiatrists
- Association of Rehabilitation Nurses
- Congress of Neurological Surgeons
- Insurance Rehabilitation Study Group
- Paralyzed Veterans of America
- U.S. Department of Veterans Affairs

Who Should Read This Guide?

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

Health-care professionals may obtain a copy of the full clinical practice guideline by calling toll-free (888) 860-7244 or at www.pva.org.

If you have SCI at or above T-6, this Guide is for you. Why? Because you have a greater chance of developing a serious condition called *autonomic dysreflexia*.*

If your injury is below T-6, this Guide may still be helpful. People with SCI as low as T-8 have sometimes developed autonomic dysreflexia.

Even if you've already learned what to do for autonomic dysreflexia, you may want to keep this Guide for reference. It may be helpful for you or for people who share in your care.

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 ensuring that health-care professionals 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 take it with you to the hospital and share it with the emergency room staff.

What Is Autonomic Dysreflexia?

It's an abnormal response to a problem in your body below your SCI. The cause is often an overfull bladder or bowel. Because of your SCI, your body

Quick Overview

Autonomic dysreflexia is an emergency condition that needs immediate attention! It's most likely to occur if you have a spinal cord injury at or above thoracic level 6 (T-6).

Autonomic dysreflexia is an abnormal response to a problem somewhere in your body. It's usually caused by a bladder or bowel problem.

Because of your SCI, your body can't respond properly to signals that something is wrong. Instead, you may develop a rapid rise in blood pressure. High blood pressure is a serious medical problem. It can cause a stroke and death.

*Words in italics are explained in the Glossary on page 10.

Here's What Happens in Autonomic Dysreflexia

1. Something is wrong. It's often 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 SCI blocks the messages 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 blood vessels in the rest of your body. The extra blood makes your blood pressure go up fast.
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:

(continued)

can't respond properly to signals that something is wrong. (Common warning signs that you might have autonomic dysreflexia are listed below.)

The important thing for you to know is that autonomic dysreflexia can be dangerous. It can cause a rapid rise in blood pressure. High blood pressure is a serious medical problem. It can cause a stroke and death.

There are two ways you may get your blood pressure down:

1. Fix whatever is causing the problem
2. Special blood pressure medicines prescribed by your health-care professional

What Causes Autonomic Dysreflexia?

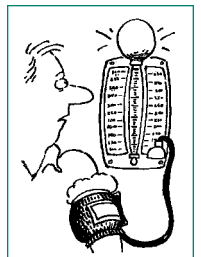
Bladder problems are the number one cause of autonomic dysreflexia. But any problem below your SCI can cause this condition.

Some of the more common causes are listed in the table on pages 8–9. You can avoid most of these causes by taking good care of yourself. The table lists things you can do to prevent autonomic dysreflexia.

What Are the More Common Warning Signs?

Although it's possible to have no symptoms, most people do. Watch for one or more of the following more common warning signs:

- A fast, major increase in blood pressure is the most dangerous sign of autonomic dysreflexia. A major increase is 20–40 mm Hg higher than usual. Many individuals who have SCI at or above T-6 have a blood pressure between 90 and 110 mm Hg systolic. (Systolic is the top number in a blood pres-



Important: Individuals' blood pressures vary. If you don't know what your normal blood pressure is, it is important that you find out.

sure reading.)

- A pounding headache
- Heavy sweating, especially in your face, neck, and shoulders. This is usually (but not always!) above your spinal cord injury
- Flushed or reddened skin, especially in your face, neck, and shoulders. This is usually above your spinal cord injury



- Goose bumps, usually above your spinal cord injury
- Blurry vision or seeing spots
- A stuffy nose
- Anxiety or jitters
- A feeling of tightness in your

chest, flutters in your heart or chest, or trouble breathing

While there may be other warning signs, these are the more common. If **any** of them appears, or if your blood pressure rises 20–40 mm Hg systolic, assume you have autonomic dysreflexia. Follow the steps in the next section.

If I Think I Have Autonomic Dysreflexia, What Should I Do?



Prompt action is essential! If you can't follow these steps yourself, ask someone else to do so. It's important to do these steps in the order 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 up higher.

Sit up or raise your head to 90 degrees. If you can lower your legs, do.

- Clothes
- Shoes or leg braces
- External catheter tape
- Leg bag straps



Here's What Happens
(continued)

Signal 1

tells your heart to slow down. (A slow heart beat is called **bradycardia**.)

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.

Signal 3

tries to tell the blood vessels in your legs and abdomen to stop squeezing. But your SCI blocks the messages from getting through. Your blood vessels keep squeezing, and your blood pressure stays high. It may even keep rising.

Bladder Management Tips

- Drink enough fluids. Ask your health-care professional about the right amount for you. You want to keep flushing out your bladder without letting it get overfull.
- If your urine is cloudy, has a bad smell, or has blood in it, call your health-care professional right away. You probably have a bladder infection.
- Be careful with drinks that have caffeine or alcohol. They can make your bladder fill up suddenly and cause you to get dehydrated.
- Checkups (often done yearly) may include bladder tests. Ask if your health-care professionals have experience with autonomic dysreflexia. Share this information and make a plan with them beforehand.

If you use intermittent catheterization:

- Stick to your schedule. Don't skip catheter sessions.

(continued)



- Abdominal binders
- Elastic hose or bandages

If you have a blood pressure kit, take your blood pressure reading about every 5 minutes to see if you're getting better.



Check your bladder.

See A (below) if you do intermittent catheterization or use an external catheter.

See B (below) if you have an indwelling catheter

A. If you do intermittent catheterization, or use an external catheter or padding:

1. Take off the external catheter or pads.
2. If you (or someone with you) has experience inserting a catheter:
 - Get a catheter.
 - Coat it with an anesthetic jelly (if available) or a lubricant jelly.
 - Insert it and empty your bladder promptly.
3. **Stop trying to catheterize your bladder if:**
 - There's no one with experience at inserting a catheter.
 - The catheter won't slip in easily.
 - Your symptoms get worse.

Instead, call a health-care professional and go to the emergency room right away. Call 911 or have someone take you. It's dangerous for you to drive if you have autonomic dysreflexia.

4. If you can insert another catheter and

your blood pressure remains elevated, go to the emergency room right away.

5. Check your urine for blood, odor, or cloudiness. If you find any of these things, call your health-care professional right away. You probably have a bladder infection.

B. If you have an indwelling catheter (a Foley or suprapubic catheter):

1. Check the tubing for kinks or twists. If you find any, fix them. If the tubing is stretched or pulling, relax it. Then tape it to keep it from pulling.
2. Empty the drainage bag.
3. If there's no urine flow, and you have experience irrigating your bladder, **gen-**

Important: If your symptoms get worse, **immediately** stop irrigating. Call your health-care professional and go to the emergency room right away!

tly irrigate your bladder with saline solution. Use a small amount: no more than 2 tablespoons or 1–2 ounces (30 cc).

4. If there's still no urine flow and someone (you or anyone with you) has experience inserting a catheter:
 - Get another catheter.
 - Coat it with an anesthetic jelly (if available) or a lubricant jelly.
 - Insert the catheter into your bladder.
5. **Stop trying to catheterize your bladder if:**
 - There's no one with experience at inserting a catheter.
 - The catheter won't slip in easily.
 - Your symptoms get worse.

Instead, call a health-care professional and go to the emergency room right

Bladder Management Tips
(continued)

- Keep your fluids to about 8 ounces (1 cup, 240 ml) an hour.
- If you drink more fluids than usual, catheterize early or add an extra session.
- Even though you may be tempted to cut back on fluids for convenience, don't. You'll increase your risk for urinary tract infection.

If you have an indwelling catheter (a Foley or suprapubic catheter):

- Check your drainage tube after transfers and turns. If you find any kinks or twists, fix them. Look for anything that clogs the catheter and clear it.
- Make sure the drainage bag doesn't get more than half full.
- Change your catheter regularly. Learn how to change it yourself or make arrangements for someone to do it for you. Also, train someone who can change it in an emergency.

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 health-care professionals.

If you're having tests, surgery, or a baby, make sure your health-care professionals are ready to monitor and manage autonomic dysreflexia if it develops.

away. Call 911 or have someone take you. It's dangerous for you to drive if you have autonomic dysreflexia.

6. Check your urine for blood, odor, or cloudiness. If you find any of these things, call your health-care professional right away. You probably have a bladder infection.

Important: If you need to go to the emergency room, ask if you can sit up. Lying down may make your blood pressure go up.



7. If you can insert another catheter and your blood pressure remains high, go to the emergency room right away.

If the warning signs go away, call your health-care professional anyway, to report the symptoms you had and what you did to correct the problem.



If the warning signs come back again, repeat these steps. Even if the warning signs go away again, call your health-care professional and go to the emergency room.



At the emergency room, make sure you:

- Tell the emergency room staff that you think you may have autonomic dysreflexia and need immediate treatment.

- Ask to have your blood pressure checked immediately.
- Request to keep sitting up as long as your blood pressure is high.
- Ask the emergency room staff to look for causes of the problem. Suggest that they check causes in this order: (1) bladder, (2) bowel, and (3) other causes.



Use the diary form on pages 11-14 and in the back pocket of this Guide to keep a record of your autonomic dysreflexia episodes. It can be helpful to you and to your health-care professionals.

What Goes in an Autonomic Dysreflexia Kit?

It's a good idea to make an "autonomic dysreflexia kit" and keep it

with you at all times. Here's what it should contain:

A blood pressure kit.

This can be cuff style or digital style. Make sure that you—or someone who can help in an emergency—knows how to use it.

A catheter and supplies.

If you use intermittent catheterization, or use an external catheter or padding, pack a straight catheter.

If you use an indwelling catheter, pack:

- an extra catheter
- insertion supplies
- an irrigation syringe
- sterile water or saline solution

Any prescription medicines you take for autonomic dysreflexia.

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

Anesthetic or lubricant jelly.

Before you insert a catheter, coat it with the jelly.

A copy of this Guide.

Keep your personal information current. (See the Autonomic Dysreflexia Diary on pages 11-14)

AUTONOMIC DYSREFLEXIA IS A MEDICAL EMERGENCY!
You need to recognize it and get the right care fast.

Common Causes of Autonomic Dysreflexia

WHAT CAUSES IT	HOW TO PREVENT IT
<p>BLADDER OR KIDNEY</p> <ul style="list-style-type: none"> • Overfull bladder • Problems such as urinary tract infection, or bladder or kidney stones • Bladder tests, treatments, or surgery, such as <i>cystoscopy</i> and <i>urodynamic tests</i> 	<ul style="list-style-type: none"> • Follow a reliable bladder management routine. (See page 4, “Bladder Management Tips.”) • Checkups (often done yearly) may include bladder tests. Ask if your health-care professionals have experience with autonomic dysreflexia. Share this information and make a plan with them beforehand.
<p>BOWEL* OR ABDOMEN</p> <ul style="list-style-type: none"> • Overfull bowel, constipation, or bowel blockage (<i>impaction</i>) • Problems such as gallstones, stomach ulcer or <i>gastritis</i>, hemorrhoids, or appendicitis • Bowel or abdominal tests or surgery, such as <i>sigmoidoscopy</i> or <i>barium enema</i> 	<ul style="list-style-type: none"> • 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 what your usual fiber intake is. 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 make a plan with them beforehand.
<p>* For more detailed information on bowel care, a complete bowel management clinical practice guideline is available at the website: www.pva.org or by calling toll-free (888) 860-7244.</p>	
<p>SKIN</p> <ul style="list-style-type: none"> • Pressure sores (pressure ulcers) • Problems such as ingrown toe nails, burns (including sun burns), or insect bites • Contact with hard or sharp things or other injuries to the skin 	<ul style="list-style-type: none"> • 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.

WHAT CAUSES IT

HOW TO PREVENT IT

SEXUAL ACTIVITY OR REPRODUCTION

- Too much genital stimulation, especially using a vibrator
 - Men: ejaculation, infection or inflammation of the testicles (*epididymitis*), or pressing or squeezing of the testicles
 - Women: menstruation, pregnancy (especially labor and delivery), or infections of the vagina (*vaginitis*) or uterus (*pelvic inflammatory disease*)
- Be aware that these activities and conditions are possible causes of autonomic dysreflexia. You may want to discuss these issues with your health-care professional.
 - 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.

OTHER CAUSES

- 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, shoes, appliances, or braces
 - Extreme temperatures (too hot or too cold), or quick temperature changes
- 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.

* For more detailed information on deep vein thrombosis (thromboembolism), a complete *Prevention of Thromboembolism* clinical practice guideline is available at the website: www.pva.org or by calling toll-free (888) 860-7244.

and in the back pocket of this Guide.)

Be sure to discuss your autonomic dysreflexia kit with your health-care professional. Ask if you should include other supplies. Also ask if your health-care professional can give you prescriptions for items in the kit.

Glossary

autonomic dysreflexia—An abnormal response to a problem in the body below a spinal cord injury. It's most likely to happen if the SCI is at or above the 6th thoracic vertebra (T-6).

autonomic nerves—Nerves in the spinal system that control involuntary action.

barium enema—An examination of the inside of the body done with a substance called "barium." This test is also called a "double-contrast examination."

bradycardia—Slow heart rate, usually fewer than 60 beats per minute.

cystoscopy—An examination of the inside of the bladder and ureter. It's done with an instrument called a "cystoscope."

deep vein thrombosis—Clots in the leg or pelvis veins. Also referred to as "thromboembolism."

epididymitis—Inflammation of the part of the testicle called the "epididymis."

gastritis—Inflammation of the stomach.

impaction (of the bowel)—Occurs when hard stool is stuck in the rectum or somewhere else in the bowel.

pelvic inflammatory disease (PID)—An infection anywhere in a woman's genital tract above the cervix.

pulmonary emboli—Blood clots that travel to the lungs.

sigmoidoscopy—An examination of the part of the colon called the "sigmoid

My Personal Autonomic Dysreflexia Diary

This Personal Diary is intended for you to use to keep a health-care record of your episodes of autonomic dysreflexia. Another copy of the Diary, which you can photocopy for re-use, appears in the back pocket of this Guide. Keep this diary and the Guide with you.

Name: _____

Address: _____

City _____ State: _____ Zip Code: _____

Phone Number: (____) _____

Social Security Number: _____ Date of Birth: _____

Date of Dysreflexia Episode: _____

Symptoms

Put a checkmark or "X" next to every symptom you have for each dysreflexia episode.

Pounding headache

Heavy sweating

Flushed skin

Goose bumps

Blurry vision

Seeing spots

Stuffy nose

Anxiety or jitters

Tight chest

Trouble breathing

Other:

Cause of Dysreflexia Episode and Comments:

Date of Dysreflexia Episode: _____

Symptoms

Put a checkmark or "X" next to every symptom you have for each dysreflexia episode.

Pounding headache

Tight chest

Heavy sweating

Trouble breathing

Flushed skin

Other:

Goose bumps

Blurry vision

Seeing spots

Stuffy nose

Anxiety or jitters

Cause of Dysreflexia Episode and Comments:

Date of Dysreflexia Episode: _____

Symptoms

Put a checkmark or "X" next to every symptom you have for each dysreflexia episode.

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Tight chest

Heavy sweating

Trouble breathing

Flushed skin

Other:

Goose bumps

Blurry vision

Seeing spots

Stuffy nose

Anxiety or jitters

Cause of Dysreflexia Episode and Comments:

Date of Dysreflexia Episode: _____

Symptoms

Put a checkmark or "X" next to every symptom you have for each dysreflexia episode.

- Pounding headache
- Heavy sweating
- Flushed skin
- Goose bumps
- Blurry vision
- Seeing spots
- Stuffy nose
- Anxiety or jitters

- Tight chest
- Trouble breathing

Other:

Cause of Dysreflexia Episode and Comments:

Date of Dysreflexia Episode: _____

Symptoms

Put a checkmark or "X" next to every symptom you have for each dysreflexia episode.

- Pounding headache
- Heavy sweating
- Flushed skin
- Goose bumps
- Blurry vision
- Seeing spots
- Stuffy nose
- Anxiety or jitters

- Tight chest
- Trouble breathing

Other:

Cause of Dysreflexia Episode and Comments:

MEDICAL HISTORY

Date of Spinal Cord Injury: _____

Neurologic Location of Injury: _____

Normal Blood Pressure: _____

Blood Type: _____

Primary Health-care Professional: _____

Phone Number: _____

Medications: _____

EMERGENCY INFORMATION

In Case of Emergency, Call: _____

Relationship: _____

Phone Number: (_____) _____

INSURANCE INFORMATION

Name of Insurance Company: _____

Identification Number: _____

Group Number: _____

Phone Number: (_____) _____

Plan Subscriber: _____