

SPINAL CORD MEDICINE

More About Autonomic Dysreflexia and Other Autonomic Dysfunctions

A Consumer Guide for People with Spinal Cord Injury



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This a second consumer that discusses autonomic dysreflexia. This guide is different from the first. It discusses autonomic dysreflexia with regards to bladder procedures, sexual activity, and pregnancy and lactation and boosting. In addition, this guide discusses other autonomic dysfunctions, specifically orthostatic hypotension, hyperhidrosis (sweating) and temperature regulation.

Note: See Appendix A for treatment of an episode of acute autonomic dysreflexia

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(Tear-off reference table)

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.

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Introduction

The autonomic nervous system controls, manages or coordinates many processes that happen without your conscious effort or awareness, such as your heartbeat, blood flow, breathing, sexual function, and digestion. After spinal cord injury, your autonomic system does not work properly and affects your nervous system's control of other parts of your body including your heart, blood vessels, body temperature control, sweat glands and more. This is called **autonomic dysfunction (AD)**. Persons with a higher-level SCI at or above T6 (neurologic level, see Figure 1) are more at risk to experience issues with autonomic dysfunction and can experience **orthostatic hypotension** (low blood pressure when sitting up), **reduced body temperature regulation**, **excessive sweating**, and **other related conditions**.

This guide reviews issues and considerations to be aware of that are related to autonomic dysfunction. It helps you recognize when your autonomic system is not working properly, and additional causes of autonomic dysreflexia.

There are many possible conditions which can cause autonomic dysreflexia which are discussed in the autonomic dysreflexia health care professional and consumer guideline. This Guide is focused on **urological procedures**, **sexual activities**, **pregnancy** (including **labor**, **delivery**, and **lactation**), and **other autonomic dysfunctions**, which can also cause autonomic dysreflexia.

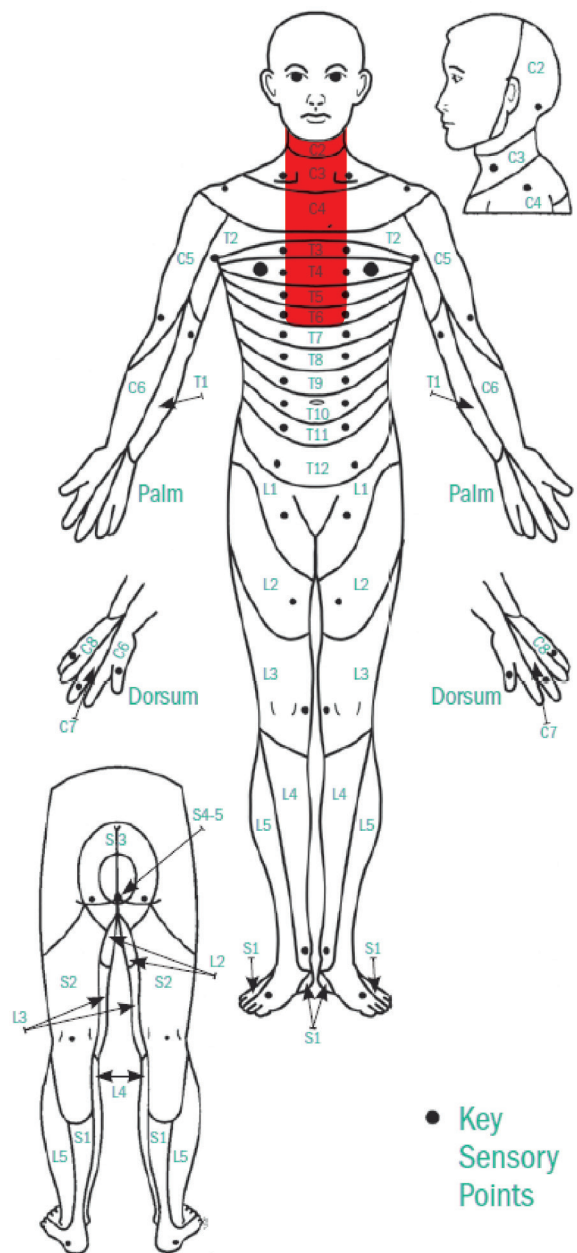


Figure 1: Spinal Cord and Injury Level

Autonomic Dysfunctions

There are many types of autonomic dysfunctions following SCI. This guide addresses several of the more common ones, which can cause episodes of Autonomic Dysreflexia. This section focuses on:

- Blood pressure control (Orthostatic Hypotension)
- Excessive sweating/Hyperhidrosis
- Altered body temperature regulation

Orthostatic Hypotension

What is Orthostatic Hypotension: Persons with high thoracic and cervical spinal cord injury tend to have a low resting blood pressure. A person can experience a further drop in their blood pressure (BP) when standing after sitting or sitting up after lying down. When the diastolic (top number of BP) drops 20 mmHg from the baseline, this is referred to as orthostatic hypotension (OH).

Why: Your nervous system controls the size of your blood vessels. The size of the vessels adjusts to maintain your blood pressure. Before your SCI, when your blood pressure was low, your blood vessels would tighten (narrow), which would make your blood pressure go up. When your BP was high, your blood vessels would relax and get bigger, and your blood pressure would lower. After SCI, your vessels may not be able to maintain your blood pressure like they did before your injury. Frequently they do not get as narrow as they did before your injury, causing your blood pressure to remain lower than it did before your injury. Your muscles also help with keeping your blood moving throughout the body. After SCI, the paralyzed muscles are not as effective at squeezing the blood out of the blood vessels in your paralyzed muscles, which also causes you to have a lower BP.

If you have low BP (OH), laying down with your legs elevated allows the blood to go back into the rest of your body and will raise your BP. Dehydration and low salt intake can also result in low BP (OH). You may also experience low BP (OH) after eating or exercising since the blood will be more likely to flow from the rest of your body to your intestines or muscles which were exercised. If your whole body has sudden spasticity, this is different from exercise and can actually squeeze the blood into your whole body and cause your blood pressure to go up. This may cause autonomic dysreflexia during the spasm, especially when laying down.

Note: Sitting up with your legs down will do the reverse and make the blood flow down to your legs and cause your blood pressure to get lower. This is why you should immediately sit up if you develop a sudden high blood pressure (autonomic dysreflexia).

What you may feel: light-headed, dizzy, feeling of faintness or unsteadiness, fatigue or weakness, blurred vision, difficulty breathing, and restlessness. Some people may develop OH but have no symptoms.

What to do: Monitor your blood pressure before you get up and after sitting. If you experience symptoms of OH, such as feeling lightheaded, lie down or tilt your chair back, put your leg rests up and wait until the symptoms resolve.

If you have ongoing difficulty managing your blood pressure, there are options:

Non-medication

- Wear compression stockings and/or abdominal binder
- Stay hydrated
- Increase salt and water intake
- Avoid excessive heat
- Move slowly from lying to sitting
- Elevate your legs

Medication

- If you continue to have difficulty maintaining your blood pressure when upright, you should seek medical advice for medication options.

Excessive Sweating/Hyperhidrosis

Sweating is a common body function to cool our bodies. After SCI, persons will typically not experience sweating below the level of injury. Excessive sweating related to SCI above and below the level of your injury can be seen independently or it can be seen during episodes of autonomic dysreflexia. Excessive sweating, regardless of environmental temperature, is called hyperhidrosis. Persons who experience this will have to change clothes, change bedding, and dry themselves off more frequently. Sweating at this extent can cause loss of water as well.

Why: Like autonomic dysreflexia, hyperhidrosis is an abnormal response to a problem in your body below your spinal cord injury. For example, it can be triggered by bowel and bladder fullness, bladder stones, or irritation to your skin.

What to do: If related to AD, follow AD guidelines for management.

- Identify the trigger and remove it. (Empty bowel/bladder, reposition)
- Assure good hydration. You may need to drink more.
- Medications such as prescription creams and antiperspirants can curb sweat production
- If excessive sweating persists, seek medical advice for further options.

Altered Body Temperature Regulation

What is body temperature regulation: Your body responds to changes in air temperature through sensors in the skin sending messages to control centers in the body. This is referred to as body temperature regulation. When you are in a cold environment, the signal sent to the brain makes your blood vessels constrict and your body shivers to get warmer. When you are in a hot environment, the body sends the brain the message of overheating. The body cools down by sweating.

Why: A spinal cord injury can block these needed sensations, and your body cannot send signals or adapt to the temperature changes. This means that you may not be able to shiver to warm up or sweat below your level of injury to cool off, resulting in hypothermia (low body temperature) or hyperthermia (high body temperature).

Hypothermia: Difficulty regulating your body temperature in the cold, defined as a body temperature less than 35°C/95°F and can be dangerous. Because of the SCI, you may be unable to shiver to warm up. When hypothermia occurs you may feel chilled, drowsy, confused, irritable and may lose consciousness.

What to do:

Prevention: Avoid temperature extremes. Avoid alcohol intake as this opens your blood vessels resulting in heat loss. Wear layers of warm clothing, assuring head, hands and feet are well covered.

Treatment: Monitor your temperature. Wrap in insulated clothing/blankets, use warm humidified air, and drink warm fluids. (Avoid heating devices especially in areas that you have poor sensation, which can cause undetected burns). You may need to seek medical attention.

Hyperthermia is difficulty regulating your body temperature in the heat, with a body temperature more than 37.8°C/100°F. Because of the SCI, you may not be able to sweat to cool off in hot environments. When hyperthermia occurs you may feel weak, dizzy, hot, dry, with headache, nausea, and visual impairment (blurry vision or spots in your vision). The danger of hyperthermia is heat exhaustion or heat stroke.

What to do:

Prevention: Wear appropriate lightweight and light-colored clothing, maintain a proper temperature-controlled room, drink cold fluids and stay hydrated, and use a water spray/fan on exposed skin.

Treatment: Move to a cooler environment, drink cold liquids, wash with cool water and rest. You may need to seek medical attention.

Urological Testing Procedures and Autonomic Dysreflexia

Urological testing is important to help evaluate your bladder and kidney function.

Two common tests to evaluate your bladder are called urodynamics, which tests your bladder and urinary sphincter function, and cystoscopy, which looks inside your bladder. These tests include filling your bladder with water. These tests are not only helpful to know about your bladder and sphincter but also help to determine if you are likely to get autonomic dysreflexia. About 40% of people with SCI above T6 get autonomic dysreflexia with a sudden increase in systolic blood pressure but no other signs or symptoms (called silent autonomic dysreflexia) the urodynamics test is also helpful to determine if you are someone who gets silent autonomic dysreflexia.

Since filling your bladder can cause autonomic dysreflexia, it is important to have the health care providers performing your tests to be familiar with autonomic dysreflexia. It is also important to minimize the possibility of autonomic dysreflexia before getting your urological testing. Otherwise, your tests may have to be cancelled or stopped in the middle of the procedure.

Note: if you are getting a renal ultrasound the radiology center may want to clamp your catheter or have you drink a lot of fluids and not empty your bladder so they can also get a bladder ultrasound. They may not be aware that bladder distention can cause autonomic dysreflexia and also may not be aware of how to treat autonomic dysreflexia, so make sure to discuss this with them and the person ordering the renal ultrasound.

Ways to prevent

- Prior to having testing, make sure to minimize other possible causes of autonomic dysreflexia by draining your bladder, having a good bowel program (getting good output with bowel care), and treating other possible causes of autonomic dysreflexia.
- Loosen any tight clothing.
- Discuss options with your health care provider whether or not to hold prescribed medications that are used to raise your blood pressure (such as midodrine) prior to bladder procedures.

Note: Be aware that if you take a medication for erections such as sildenafil (Viagra) or others, and develop autonomic dysreflexia, not to take anything that contains nitrates such as nitropaste to bring down your blood pressure, since the combination of these types of medications and nitrates can cause a sudden severe drop in your blood pressure (severe hypotension). Make sure to notify your health care provider of your specific medications prior to the procedure.

Sexual Activities and Autonomic Dysreflexia

If your SCI is at T6 or above, your sympathetic nervous system, also known as the “fight or flight” system, can cause you to get autonomic dysreflexia. The sympathetic system becomes active during sexual activities, including manual stimulation and intercourse, especially at time of ejaculation in men and orgasm in women. Sexual activities are any activity that result in arousal, ejaculation, and/or orgasm. In addition, induced ejaculations, or sperm retrieval, usually with a vibrator to obtain sperm for pregnancy, can also cause autonomic dysreflexia. Ejaculations from a vibrator can cause very high blood pressure. Although the autonomic dysreflexia occurs only while having an ejaculation or orgasm and then goes away, very rarely it may not. If your blood pressure does not go down by stopping the sexual activity and sitting up, look for other causes of autonomic dysreflexia. If none are found seek immediate medical care. The autonomic dysreflexia can be worse if you also have other causes of autonomic dysreflexia such as a full bladder, constipation, or bladder infection.

Ways to prevent

- Prior to involvement in sexual activity consult with your medical provider and learn about your resting blood pressure.
- Prior to sexual activity, and having a possible ejaculation or orgasm, make sure to minimize other possible causes of autonomic dysreflexia by draining your bladder, having a good bowel program, and treating other possible causes of autonomic dysreflexia.
- Loosen any tight clothing.
- Do not take any medications that are used to elevate your blood pressure such as midodrine or pseudoephedrine. Discuss with your provider about holding off on these medications prior to sexual activity.
- If you start to get symptoms of autonomic dysreflexia, stop what you are doing and sit up with your legs down.
- If your symptoms do not go away and you can't find any other causes immediately call emergency services.
- If sperm retrieval is being done, make sure that the health care providers obtaining the sperm are familiar with how to treat autonomic dysreflexia. They will often pre-medicate with medications to help to keep your blood pressure from rising too high.

Note: Be aware that if you take a medication for sexual activity such as phosphodiesterase inhibitors (sildenafil [Viagra]) and develop autonomic dysreflexia, do not take anything that contains nitrates such as nitropaste to bring down your blood pressure, since the combination of this medication and nitrate can cause a sudden severe drop in your blood pressure (severe hypotension) and you may pass out. Make sure to notify your health care provider of your medications and what to avoid prior to the procedure.

Pregnancy, Labor and Delivery, and Lactation and Autonomic Dysreflexia

Women with spinal cord injury at or above T6 are at risk of AD during pregnancy, labor and delivery, and after delivery. AD can lead to severe consequences for mom and baby and not all health care providers are aware of AD. When contemplating pregnancy or early into pregnancy, women with SCI should be seen by a team of providers (Obstetrics, Physical Medicine and Rehabilitation, Anesthesiology, and Urology) to plan for a healthy pregnancy through post-partum.

During Pregnancy:

- You may experience headaches and nausea early on, which is common during pregnancy. If you experience a pounding headache, it could be a sign of AD.
- Take care to manage your bladder and bowel and protect your skin during pregnancy to reduce your chance of AD.

Labor and Delivery:

- Women with SCI above T10 can have diminished sensation or absence of pain resulting in inability to recognize labor symptoms. You should undergo weekly checks beginning at 28 weeks for effacement (thinning) and dilation of the cervix. If your spinal cord injury is at or above T6 you may require early inpatient hospitalization to monitor cervical dilation and progression of labor due to the risk of AD.
- Anesthesia is suggested to prevent AD during labor. Discuss management such as spinal or epidural anesthesia with your OB/Anesthesiology team.

After Delivery: Lactation and Orthostatic Hypotension

- Breastfeeding, breast engorgement or mastitis can also trigger AD.
- Closely monitor your blood pressure if you decide to breastfeed. Be aware of signs and symptoms of AD.
- If you do have symptoms of AD check your BP. If elevated, sit up and stop breast feeding. Look for other possible causes of autonomic dysreflexia. If none are found discuss your AD during breast feeding with your health care provider to get further advice.
- Orthostatic hypotension, or low blood pressure, can occur in women who have no control over the abdominal muscles. You may feel faint or dizzy when sitting for several days after delivery. This can be prevented and treated by sitting up slowly, wearing compression socks, and/or abdominal binder, and staying hydrated. (Also see the “Other Autonomic Dysfunctions -Orthostatic Hypotension section

Dangers of Self-Induced AD: Boosting

Individuals with SCI experiencing low blood pressure are aware that this could contribute to fatigue, cognitive dysfunction, and difficulties with sports related activities. Some Paralympic athletes with SCI are using a dangerous technique called “boosting”, a deliberately induced autonomic dysreflexia to gain an advantage in competition. Athletes who boost can end up experiencing seizures, myocardial infarction (heart attack), pulmonary edema (fluid in the lungs), and cerebral hemorrhage.

In particularly serious cases, boosting and autonomic dysreflexia can even result in death. As this is a health threat, the International Paralympic Committee (IPC) forbids athletes to compete in the hazardous state of autonomic dysreflexia.

AUTONOMIC DYSREFLEXIA IS A MEDICAL EMERGENCY!

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

Autonomic Dysreflexia (AD) is a sudden increase in blood pressure, at least 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 at 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
- May just have high systolic blood pressure with no other symptoms “silent autonomic dysreflexia”

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 Dysreflexia and these are not working, immediately contact your health care professional or emergency department.*

Scan QR code
for the Autonomic
Dysreflexia
Consumer Guide



Scan QR code
for Clinical
Practice Guidelines



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Table 1: Ways to Prevent Additional Autonomic Dysfunctions

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Ways to Prevent Additional Autonomic Dysfunctions	
What to Do:	
<p>Orthostatic Hypotension (OH)--></p>	<ul style="list-style-type: none"> • Monitor your blood pressure before you get up and after sitting. If you experience symptoms of OH, lie down or tilt your chair back, and wait until the symptoms resolve. • If you have ongoing difficulty managing your blood pressure, there are options: <ul style="list-style-type: none"> Non-medication -Wear compression stockings and/or abdominal binder -Stay hydrated -Increase salt and water intake -Avoid excessive heat -Move slowly from lying to sitting -Elevate your legs Medication -If you continue to have difficulty maintaining your blood pressure when upright, you should seek medical advice for medication options.
<p>Excessive Sweating/ Hyperhidrosis --></p>	<ul style="list-style-type: none"> • Identify the trigger and remove it. (Empty bowel/bladder, reposition) • Assure good hydration. You may need to drink more • Medications such as prescription creams and antiperspirants can curb sweat production • If excessive sweating persists, seek medical advice for further options.

Tear sheet here

Ways to Prevent Additional Autonomic Dysfunctions

What to Do:


Hypothermia -->

- Avoid temperature extremes.
- Avoid alcohol intake as this opens your blood vessels resulting in heat loss.
- Wear layers of warm clothing, assuring head, hands and feet are well covered.
- Monitor your temperature.
- Wrap in insulated clothing/blankets
- Use warm humidified air, and drink warm fluids. (Avoid heating devices especially in areas where you have poor sensation).

Hyperthermia -->

- Wear appropriate lightweight and light-colored clothing
- Maintain a proper temperature-controlled room
- Drink cold fluids and stay hydrated
- Use a water spray/fan on exposed skin.
- Move to a cooler environment
- Wash with cool water and rest.

You may need to seek medical attention!

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CLINICAL PRACTICE GUIDELINES



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