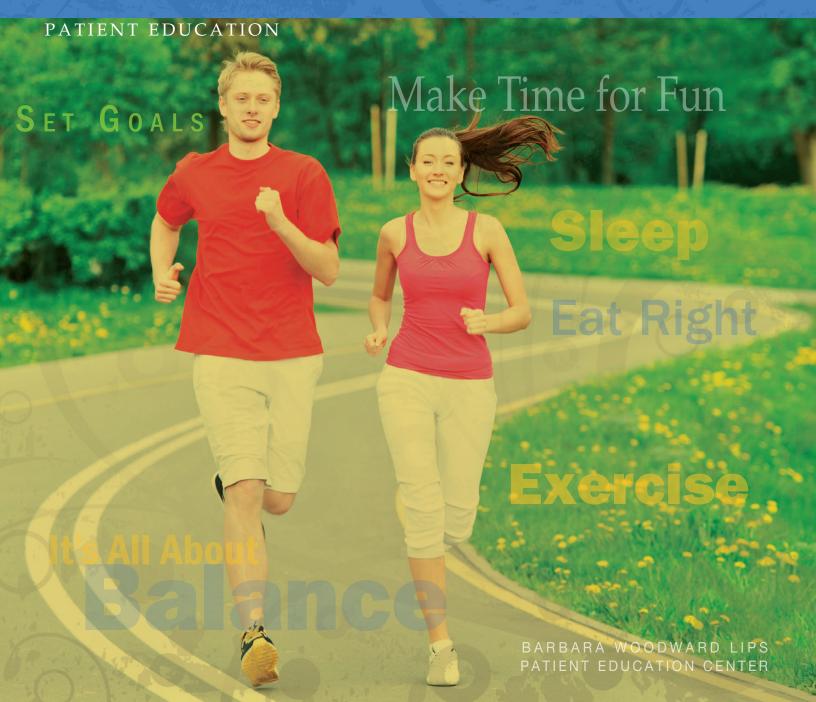


Teens + Autonomic Dysfunction



Autonomic dysfunction is a physical illness. When you have autonomic dysfunction, your blood flow, body temperature, breathing, and gastrointestinal system are out of balance. These aspects are all regulated by your **autonomic nervous system**. This is part of your nervous system that you can't control.

Have you ever heard of any of these terms? They fall under the category of autonomic dysfunction:

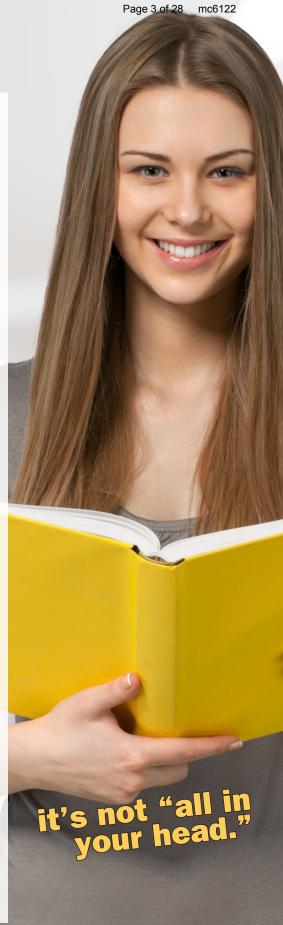
- Autonomic instability
- Orthostatic intolerance
- Dysautonomia
- POTS (postural orthostatic tachycardia syndrome)

who gets autonomic dysfunction?

Anybody can get autonomic dysfunction.
But it's more common for teens who are:

- Caucasian.
- Female.
- High achievers successful in school, athletics, music, work, etc.
- Flexible or double jointed.

Autonomic dysfunction in teens usually starts within a year after puberty begins.



what is the autonomic nervous system?

The autonomic nervous system controls things you may not think about. For example:

Heartbeat

Skin temperature

Breathing

Blood flow

Digestion

Normally, the autonomic nervous system sends messages, or signals, from the nerves to the muscles that surround your blood vessels. The muscles then do as they are told.

They tighten, which forces blood to flow faster through a smaller space. Or,

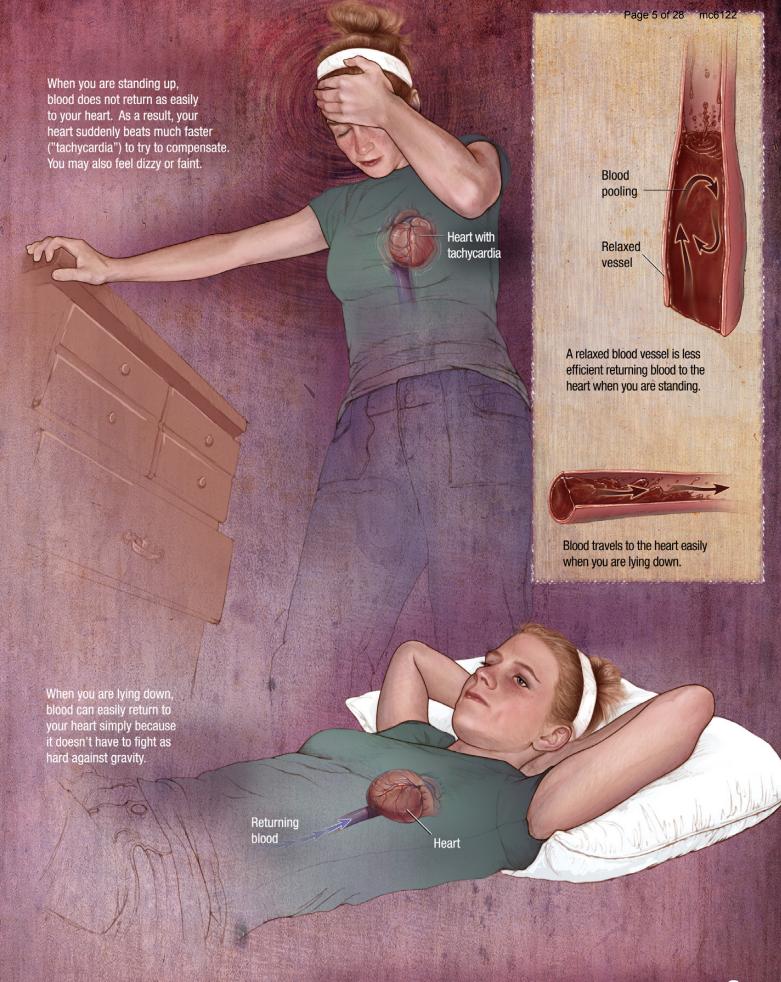
• They relax, which allows blood to flow more slowly.

When the autonomic nervous system doesn't work the way it should...

your circulation slows down and the right amount of blood doesn't go where it should. Some of the blood even pools, or puddles, in blood vessels of the lower part of your body.

In some ways, a blood vessel is like a river. When the river is wide, the water in it tends to pool and run slowly downstream...

When the river narrows, water is forced to flow much more quickly through the smaller space.

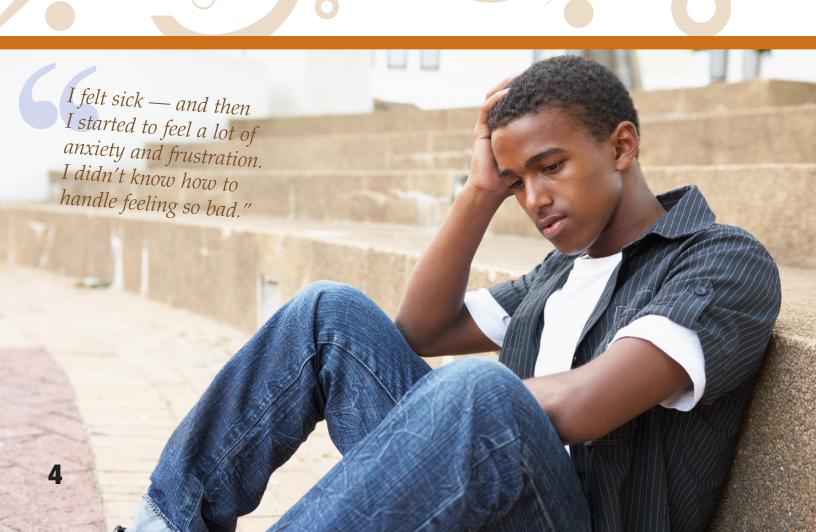


COMMON SYMPTOMS

When the autonomic nervous system is not doing its job, you may experience one or more of these symptoms:

- Dizziness/light-headedness
 Lots of sweating
- Fainting
- Being tired all the time (fatigue)
- Headaches
- Stomach pains or cramps
- Nausea
- Difficulty concentrating or "brain fog"
- Vision changes or loss of vision
- Feeling hot or cold

- Flushing (reddened skin, often the face, neck and chest)
- Increased heart rate
- Chest pain
- Weakness in your legs
- Color changes in your legs (blue or purple discoloration)
- Mood changes, including feelings of anxiety or depression





It was hard for me to get food down and keep it down. I literally got sick every time I ate. I was exhausted, I was dizzy, and I had blackouts. I was sleeping a lot, but I didn't have any energy. It wasn't good."

what about triggers?

Sometimes teens can connect their symptoms with a specific event, called a trigger. Some triggers we know are:

- A sudden illness, like a cold or another respiratory infection, an intestinal viral infection, "mono" (mononucleosis), or a mono-like infection.
- An injury.
- Surgery or a stay in the hospital.

How is this diagnosed?

Depending on which symptoms you have, your health care provider may order some tests. There are two goals for doing that:

- To rule out other medical conditions that could cause similar symptoms.
- To confirm how well or not your autonomic nervous system is working.

Did you know...

Hot showers and baths cause your blood vessels to relax. This can make you feel dizzy or lightheaded. If you typically feel dizzy in the shower, try drinking water before and after you shower. Or take a cooler shower than you usually do.





Salt. Add as much salt — to EVERYthing — as your taste buds can handle.



Take in a LOT of fluid. How much fluid? That answer differs for every person. Drink at least 2 to 4 liters every day. (1 liter = 32 ounces.) The majority of this fluid should be water. Your urine should be clear and you should go to the bathroom at least 4 times per day.



Exercise regularly. Work with your care team to develop an exercise program. They will consider your starting point and help you set realistic goals for your rehabilitation program. Make a commitment to do aerobic exercise every day!



Prescription medications. Take your medications as directed. Even if you begin to feel good, don't stop taking any of your meds unless you first talk to your doctor.



Set priorities and goals. You may have certain times of the day when you have more energy than other times. Make a daily plan so you can do what you have to do — and still make it through the day.

Sleep. Get at least 8.5 to 9.5 hours of sleep each night. Avoid naps because they can mess with your usual sleep rhythm.

School. If you are not going to school right now, talk to your family and your teachers and make a plan to get back to school full time as quickly as possible. **Teens who go to school recover more quickly!**

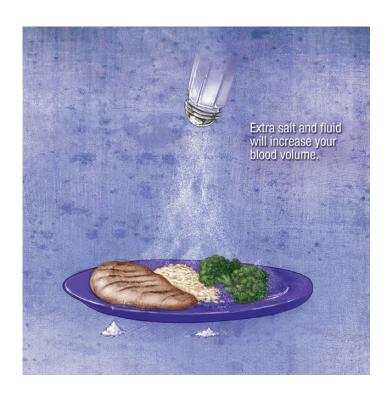
Support system. This is SO important! Stay involved with your family, friends, psychologist, and any other people you can turn to for support.

Salt + Fluids

Taking in extra fluids pumps up the volume in your blood vessels. This increases your blood flow, and that improves your circulation. With better circulation, you may be able to avoid feeling dizzy and lightheaded. And all of this can help regulate your body temperature too.

BUT, if you increase your fluids without adding salt...

You'll spend most of your day in the bathroom! Salt helps your body hold fluid. That's the goal. So, while you're drinking extra fluids, take in as much salt as your taste buds can handle. You can use any kind of salt — table salt, sea salt, garlic salt, onion salt, seasoned salt, etc.



I basically focus my day on drinking enough fluids and getting enough salt to maintain good blood flow."

Make it a goal to...

- Drink 2 to 4 liters of non-caffeinated fluid every day. That's equal to about 8 to 16, 8-oz. glasses a day. Most of your fluids should be water. Beware of sugary drinks. The empty calories could pack on pounds, cause cavities and delay your return to good health.
- Check your urine color. When you get out of bed in the morning, your urine is usually dark because it's concentrated. Your kidneys concentrate your urine at night so you are not up going to the bathroom. During the day, however, your urine should be clear. This means you are well hydrated.
- Avoid caffeinated fluids. Caffeine is a diuretic it pulls water out of your tissues and organs. (This makes you go to the bathroom more!) Caffeine affects your nerves too, and it can make you more irritable which could increase your pain. It also contributes to headaches and poor sleep.
- **Get a water bottle.** Some teens find that a certain type of water bottle affects how much they drink. Others say that they drink more water when the water is a certain temperature. Try some different ways to drink your water and find out what works for you.
- Add salty foods, like pizza, to your otherwise healthy diet.
- Try Nuun[™] or other electrolyte tablets. They can be dissolved in water as a salty fluid option. Bonus: they don't have sugar or artificial sweeteners!

Peanut butter

Nuts and trail mix

- Beef or turkey jerky

- Increase your salt intake. Add salt to your meals and try salty snacks like:
 - Pretzels and popcorn
 - Pickles
 - Cheese and crackers
 - 61 1 1
 - Sunflower and pumpkin seeds
- In the morning, drink 8 oz. of a salty fluid before you get out of bed. Examples include tomato juice, V-8TM, GatoradeTM, PoweradeTM, and PropelTM. Lie in bed for 10 to 15 minutes after that, to give the fluid time to circulate in your body. This helps reduce dizziness.



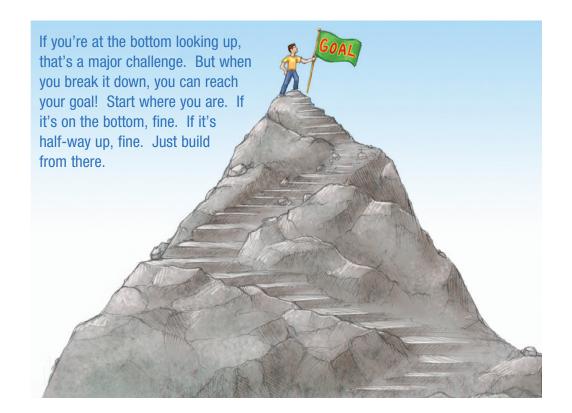
Exercise!

IT'S THE MOST IMPORTANT STRATEGY in your fight against autonomic dysfunction!

The goal is 60 minutes of movement daily. Ideally, you want to do two things every day:

- Cardio (aerobic) exercises. These exercises boost your heart rate over a longer period of time. This exercise conditions your heart and blood vessels. Do this before dinner time, so it won't affect your sleep.
- Other activities. This doesn't have to be aerobic activity. It's just some kind of activity that keeps your body moving. Examples include yoga, pilates, tai chi, strength training, martial arts, and shooting hoops.

At first, 30 minutes of cardio every day seemed impossible...
But I started slowly and added a few minutes each day. And I stuck to it. I can't believe the difference it's made in my life! My energy level is up, and I feel a lot better!"



How does exercise help you?

Exercise reconditions your body. It:

- Strengthens your muscles and builds your stamina.
- Retrains your muscles to improve your blood flow.
- Decreases fatigue and pain.
- Revs up your heart and increases your circulation which gives you more energy.
- Helps you sleep better at the end of the day.

As a bonus, exercise causes your body to release endorphins. These are like "happy hormones." They decrease your stress and help you feel better — more self-confident!

Start where you are...

- It's okay to start with a small amount of exercise. This helps you feel and be successful. You may need to start with a brisk walk of 5 minutes or so. Gradually build up your cardio activity. Add 1 to 2 minutes every 2 or 4 days. If there are days when you can't add time, it's okay.
- This isn't an "all or nothing" thing! If you do too much today because you feel good, you may feel really worn out tomorrow. But no matter how tired you feel tomorrow, you still need to exercise. It may be difficult to exercise when you're having a tough day, but your exercise/activity plan should be non-negotiable.

Wait, before you start...

To help you maintain your blood flow, be sure you get plenty of fluids before, during and after exercise. You could drink water or 8 ounces of a salty fluid, like V-8, Gatorade or Propel. If you have this drink awhile before you start the activity, it may help you avoid feeling dizzy as you exercise.

- Make a goal. Making a commitment to do cardio exercise every day may seem difficult at first especially if you aren't used to exercising. But it's worth it. Aim for 60 minutes daily — 30 minutes of cardio and 30 minutes of other activity — as your ultimate goal.
- Check your goals against your STEPS treatment plan every week. Make adjustments when needed.
- Consider working with a personal trainer. A lot of people do this to help them get a kick-start on their exercise.

Cardio is the key to your recovery!

Cardio exercise raises your heart rate for a continuous (sustained) period of time. It should be done at a vigorous pace, one that makes you a feel sweaty and out of breath.

When you are breathy, you can say about a five-word sentence, then you need to take a breath before you can talk again. If you can comfortably have a full conversation while you do your cardio exercise, you're not breathing hard enough to call it a cardio workout. This is called a "talk test."

Cardio exercise should be done when you are standing. Try some of these options:

- Use an elliptical.
- Go for a hike, brisk walk or jog (outdoors or on a treadmill).
- Go for a bike ride, ride an upright stationary bike or try a cycling class.
- Dance or do Zumba.
- Do some kickboxing.
- Play soccer.

You can also find a lot of DVDs with great cardio workouts.

The goal is to do 30 minutes of cardio exercise every day.

You can start with a 5- to 10-minute workout and add 1 to 2 minutes every 2 to 4 days until you reach that goal. Ask your health care team to help you develop an exercise plan that will work for you.





Strengthening exercises (large-muscle exercises)

Think of strengthening exercises like a JUMP-START for your body.

- Do the 3 exercises below every morning, right after you wake up. They'll increase your blood flow and help you feel better right away!
- After you get going with your cardio and other-activity exercise program, talk
 to your doctor or physical therapist about adding more strength training to your
 week 2 to 3 times per week. Other teens have said they felt AMAZING when
 they kicked up their activity a notch!

Do 25 repetitions of each of these exercises every morning.

1. Biceps curls with 3- to 5-pound weights. Stand with your feet shoulder-width apart. (You can also sit on the edge of your bed to do this exercise.) Hold the weights in your hands at your side, with your palms facing up and your elbows slightly bent. Keep your abs tight, your back straight and your arms close to your sides as you raise the weights.

Slowly raise the weights *toward* your collarbones; stop before you fully flex your elbows. Keep your wrists straight. In one smooth movement, lower your arms at the same "speed" with which you raised them. Repeat this movement 25 times.

- **2. Heel raises.** Stand with your hands at your sides and your feet slightly apart. Rise up on the balls of your feet (the pads that sit behind your toes). Hold for 3 seconds. Return to starting position. Repeat 25 times.
- **3. Squats.** Stand with your feet shoulder-width apart. Bend your knees and slowly lower your upper body as if you were going to sit down in a chair. Hold for 3 seconds. Return to starting position. Repeat 25 times.

You can do squats with your back against a wall or door too. Make sure you can see your toes sticking out beyond your knees when you do these.



Prescription medications

Medicine can't cure autonomic dysfunction. But for some people, prescription medications help manage the symptoms. Your doctor will decide if medications might be a helpful part of your plan.

- Some medicines (alpha-adrenergic) tell your blood vessels to tighten up. This may help your circulation.
- Beta-blockers keep your blood vessels from relaxing too much. This helps keep your blood flowing better.
- Drugs affecting the serotonin activity can help moderate some body responses. They may reduce your feelings of dizziness and weakness too.

Take all of your prescribed medications as directed. Be sure to tell your doctor about any side effects right away. **Do not stop taking your meds if you start to feel better.** Check with your doctor first.

Helping to regulate your body's signals

Your body has three systems that work together to control how narrow or wide your blood vessels are:

- Serotonin (SSRI)
- Beta (ß)
- Alpha (α)

If one or more of these systems isn't working well, your doctor may prescribe medication. Meds can help regulate the body's signals. When the signals work well, an adequate amount of your blood will get back to your heart when and how it's supposed to. This should help you avoid having symptoms.

Non-prescription medications

People with autonomic dysfunction sometimes have other health problems at the same time. You need to make sure that every health condition you have is taken care of.

- Many teens are low on iron stores. A ferritin test may be ordered to identify this. If needed, you may be told to take an oral iron supplement.
- Many teenagers, especially those with pain, don't get enough vitamin D. You may be told to take a supplement for this.

Set priorities and goals

Take your life back!

It's going to take some work. You're going to have to push your body to do things it doesn't want to do. Maybe you can't do everything you want to do, at least not right away. But you CAN do what you have to do!

I've always set goals for myself, even little goals, like getting up and walking every day. And big goals like going to college and getting a degree."

Other teens have offered these tips:

- Pace yourself. Think about moderation don't overdo it and don't underdo it. When a
 person "underdoes it," it leads to withdrawal and isolation. It also means that your body
 won't be as well conditioned. If you overdo it, you could "crash" and just stay in bed all
 day.
- Give yourself a break when you need one. Sometimes, we learn how to prioritize by making plans that are just too big. We live and we learn. Take a short break if you need to. But then go back and tackle that task or goal!
- Ask for help when you need it. Strong people have support systems, and they know how to use them.

If you don't push it, you'll never get past it!

Make a PLAN and stick to it

How are you going to balance your priorities throughout the day? Write down what you're going to do each day to take control of your life. Include things like:

- What time you're going to get up in the morning.
- When you're going to exercise.
- When you'll be at school.
- When you'll do your homework.
- What you're going to do for relaxation and fun.
- When you're going to bed.

Ask your parents to help you follow your schedule — even when it's hard.

Sleep

Getting a good night's sleep isn't always easy, thanks to changes in your body clock, a jam-packed schedule and a mind that won't quit. But it is really, really important!

This is a REALLY important daily goal

For you, getting a good night of sleep — every night — is one of the keys to your recovery. Healthy sleep helps:

- Your fatigue level go down.
- Your energy level go up.
- You feel better.
- You think better.

You even look better when you get healthy sleep on a regular basis!

All of this helps you do better at school, sports, music, and work!

Your body is like a car, sort of

You wouldn't expect to drive across the country on one tank of gas, would you? Your body is like that. You really do need healthy sleep & energy to recover from autonomic dysfunction. Most teens need between 8.5 and 9.5 hours of sleep each night.



Tips for success

- Stay away from pop, sugar and big meals two to three hours before you go to bed.
- Exercise. Daily exercise will help you sleep. Stop exercising at least two hours before bedtime.
- Clear your mind. Before bedtime, it may be helpful to write down anything that's on your mind, like tomorrow's todo list. Do 10 minutes of deep breathing too. (See "For more information.")
- Make a bedtime routine. When you do the same things every night before you go to bed, your brain and body get the signals that it's time to sleep.
- Avoid all screen time 30 minutes before you go to bed.
- Avoid naps!
- If you sleep in for an hour or so on the weekend, that's fine. But if you sleep really late Saturday or Sunday mornings, it means you didn't get enough sleep during the week. Don't let that happen again! Get enough sleep, even on school nights!
- If you're sleeping in a lot on the weekends, it'll be harder to fall asleep at night. And it'll be a LOT harder to wake up on Monday mornings.

School

6 tips for success at school

- **1. Plan ahead.** If you want to have a good day, make a plan and make it happen! Prioritize your day. Focus on the things you need to do. Take your water bottle and salty snacks.
- **2. Practice moderation and relaxation.** Take a few moments throughout the day to relax and release the tension from your body. Do some deep breathing. Remember: You made it to school! The best thing you can do now is stay there. If you need to take a quiet moment, ask to go to the nurse's office, the library or another quiet room at school. Then go back to class as soon as you can.
- 3. Revise your expectations. If you're tired, having a hard time concentrating or worried because you can't do as well as you'd like, remember this: Your goal is simply to stay at school and do the best you can. You may want to decrease the number of AP or honors classes you take. Adjust your schedule if you have to, but don't give up!
- **4. Focus on problem-solving.** Focus on things you can do and control, such as fluid, salt and activity. Don't focus on things you can't do or control. Throughout the day, try to break problems down as they come up. Focus on small goals throughout the day.
- **5. Practice positive self-talk.** Focus on what's going right in your life; don't think about your symptoms all the time. Remind yourself that you've made it through tough days before, and you can do it again. "Do your best and forget the rest!"

6.	Have a plan for a difficult day. When you begin to		
	struggle, you should have a plan for that too. Decide		
	now what you'll do if things get bad; know where		
	you can go to relax; and know who you can talk		
	to. Tell your support people now that you may call		
	on them for some help. They'll probably be more		
	responsive faster — when you really need them. Put		
	notes here about your plan:		



You can only stay home from school if you have a severe injury or an illness that could make other people sick.



Here's a tip

If things aren't improving, if you feel like you're getting off track or if you just want some new ideas on how to handle something, talk to a member of your health care team.

No matter how difficult the day is, you still have to do these things. (Write your list here.) **These tasks are not negotiable.** You have to do them no matter how you're feeling today.

- •
- •
- •
- •

Support System

You know that what you're feeling is real. But some people may not understand what you're going through. Some people may even say, "But you don't look sick."

It's helpful to have someone you can call and say, "This day stinks. Can you distract me for a while?" If you're feeling down, even just a short distraction can help you get back on track!

Your support system

Here's some advice from teens who have told people about their condition:

- Think about the people you feel close to, the people who you can be honest with. Who are you sure will listen 100% and help in some way if they can? It may help to make lists of friends, coaches, teachers, relatives, and even neighbors.
- Decide how much you want to tell each of those people about your condition. You can tell really close people more, but just share the basic info with others. Often all they need is a short explanation.
- Tell your closest friends and family if you want to. Remember: you can tell as much, or as little, as you want.
- Tell people that if they have questions at any time they can feel free to ask. You'd rather have them ask than to believe information that isn't right.
- Talk about your feelings (anger, sadness, etc.)
 with your friends and family. You don't have to
 focus on your physical symptoms. Focusing on
 symptoms makes them worse!

On the difficult days...

Even if your friends are supportive, it may be tough to stay in touch when you can't always do the usual activities. If you don't feel like going out, ask your friends to hang out at your house. Order pizza (add some salt!) and watch a movie. (You could even do a few squats while the movie is starting.)

You need a professional support system too

Family and friends are great. Your doctor and the nurses are great too. A psychologist can be a really important member of your support team. Psychologists can guide you through cognitive behavioral therapy.

Along with following your STEPS, it is important that you continue to receive medical care from your primary care physician. You can still get sick, even though you have this condition. Your primary care provider can help you maintain your overall good health. If you begin experiencing sudden, new symptoms, please call your usual (primary) health care provider first. He or she can:

- Help you follow your plan.
- Help you work through any other issues you may be dealing with, such as frustration, anxiety, anger, perfectionism, or depression.
- Show you ways to manage your pain and fatigue.
- Help you get back to a more active lifestyle.

Hanging out with friends makes me feel like things are getting back to normal. Even when it isn't easy to find the energy, it's definitely worth it."

My plan to beat autonomic dysfunction

1. I will get up at a.m. daily.				
2. I will do some strengthening exercises at	a.m., when I g	a.m., when I get out of bed each day.		
3. I will practice relaxation techniques for	minutes at	a.m./p.m. daily.		
4. I will start my cardio exercise program with _ and add 1 to 2 minutes every 2 to 4 days unti I'll do this at time every day.	ll I reach my goal of 30 mi			
5. Time-management techniques I will use:				
6. Stress-management techniques I will use:				
7. To keep me from doing too much or too little	today, I will:			
8. To help me relax before I go to bed, I will do the following routine:				
9. I will go to bed atp.m. on sch	ool nights and	p.m. on weekends.		
10. Two things I will do to improve my physical, emotional or spiritual health are:				



- **?** Can people with autonomic dysfunction drive? Yes, as long as they don't get too dizzy or faint while sitting down.
- **?** Can I get a handicap parking sticker? No, this doesn't qualify for handicap parking. And remember, you need 60 minutes of exercise every day!
- ? Should I wear a medical alert bracelet for my autonomic dysfunction? Usually this is not recommended. You should get emergency care when it's needed for any reason. You don't need to focus on how your condition may make you a little "different" than other teens.
- ? Do I need an individualized education plan (IEP) or other plan at school? While recovering, some teens need to get more fluids and salty snacks. And they need breaks to move around. If you have been out of school for a while and you're working your way back to full days in school, at first you may need shortened school days. This is a temporary situation for about 4 to 8 weeks. After that, you need to work up to full school days.
- ? Should some people with autonomic dysfunction get IV fluid therapy? Currently, there is no evidence to support the idea that IV fluids are better than eating more salt and drinking more fluids. There are also some big risks related to IV fluid therapy.

Do what you need to do to get back into school! Kids who stop going to school develop more symptoms, not fewer! Work with your school to find a plan that works for your recovery.

? Are there any special precautions I should take if I need surgery, such as getting my wisdom teeth removed? It is really important that you tell your surgery team about your condition. They will need to monitor your blood pressure closely and deal with any unexpected drops in the pressure.

Also, you should:

- Maximize your fluid and salt intake before and after the procedure.
- Minimize your use of opioid pain medication.
- Be active as soon as possible after the procedure.
- ? I'm sick with a cold or other illness. Which therapies (such as over-the-counter medications) are safe to use with autonomic dysfunction? Medications don't help much for colds. And sometimes they can mess up your blood flow. Continue to follow your treatment plan while you have a cold. If your nose is congested and you want to unblock the congestion, you may use normal saline nose spray or AfrinTM for 2 to 3 days.
- ? I am sick with mono. My autonomic dysfunction symptoms seem to be getting worse (or are coming back). What should I do? Maximize your fluid and salt intake, and make sure you continue your daily exercises!
- **?** Should I wear compression stockings? For some people, compression stockings are very helpful. If you use them, the stockings should be between 15 and 30mm of pressure (measured).
- ? Do I see my autonomic dysfunction specialist for ALL of my medical issues acne, ear infections, etc.? It is important that you continue to see your primary care provider. Contact him or her when you feel sick. Also continue to schedule regular check-ups with your primary health care provider.

Take your life back!

Living with autonomic dysfunction isn't easy. But every day that you stick to your plan, you are one step closer to recovering.

- Focus on what you CAN DO. Don't focus on your pain and symptoms.
- Remember to follow your STEPS!
- Practice positive self-talk. It works!
- Eat right. Along with sleep, it's like fuel for your recovery.
- Relax. Really relax. Try deep breathing, muscle relaxation and guided imagery. (See "For more information," below.)
- Celebrate your accomplishments!
- Have fun and laugh!

As you work your plan, you will feel stronger and better able to manage your life. Changes won't happen overnight. It will take one to two months of making progress before you're likely to see changes. But keep at it! It will be worth it, and YOU ARE WORTH IT!



At first, I was really angry at my body for making me feel so bad. But then I decided I was going to beat this. I refuse to give in to autonomic dysfunction! Sticking to my STEPS plan — even when it's hard — is my secret weapon. These STEPS are helping me get my life back!"

For more information

To learn more about how to relax, ask your health care provider for *Teens* + *Relaxation*, Mayo Clinic brochure MC2923-01.

If you have questions after reading this, contact your Mayo health care provider.



BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal Mayo Clinic patient of more than 40 years and a self-made business leader who significantly expanded her family's activities in oil, gas and ranching. Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. By naming the Barbara Woodward Lips Patient Education Center, Mayo honors her generosity, her love of learning, her belief in patient empowerment and her dedication to high-quality care.

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