MAYO CLINIC

PATIENT EDUCATION

Teens + Autonomic Dysfunction



BARBARA WOODWARD LIPS
PATIENT EDUCATION CENTER

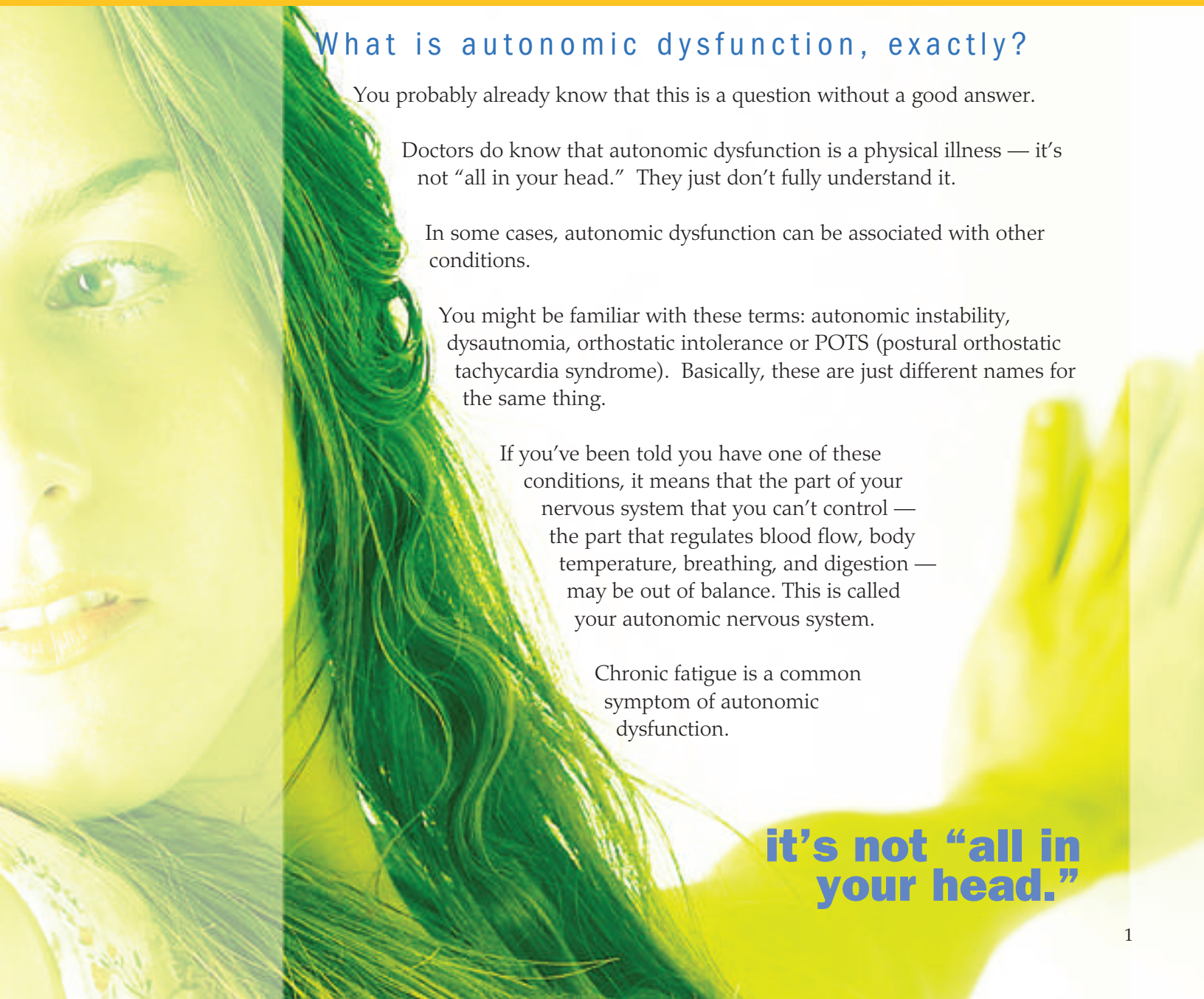
Introduction

Your doctor says you have autonomic dysfunction. You probably have a lot of questions about what that means.

This booklet explains what it means to have autonomic dysfunction.

You'll read what autonomic dysfunction is and what you can do to feel better.

You'll also hear from some teens with autonomic dysfunction. Their experiences might give you ideas about things you can do to feel better.



What is autonomic dysfunction, exactly?

You probably already know that this is a question without a good answer.

Doctors do know that autonomic dysfunction is a physical illness — it's not "all in your head." They just don't fully understand it.

In some cases, autonomic dysfunction can be associated with other conditions.

You might be familiar with these terms: autonomic instability, dysautnomia, orthostatic intolerance or POTS (postural orthostatic tachycardia syndrome). Basically, these are just different names for the same thing.

If you've been told you have one of these conditions, it means that the part of your nervous system that you can't control — the part that regulates blood flow, body temperature, breathing, and digestion — may be out of balance. This is called your autonomic nervous system.

Chronic fatigue is a common symptom of autonomic dysfunction.

it's not "all in your head."

What is the autonomic nervous system?

The autonomic nervous system controls things we don't think about such as:

Heartbeat Breathing Digestion

Skin temperature Blood flow

Normally, the autonomic nervous system sends messages or signals from the nerves to the muscles that surround the blood vessels, controlling blood flow to all parts of the body. The muscles tighten or relax, according to the signals they receive.

What happens if the autonomic nervous system doesn't work the way it should?

If the signals telling your blood vessels to loosen and contract aren't doing their job, blood can pool in your body and your circulation can slow down.

Think of a blood vessel as a river (Figure 1). When a river is wide, the water in it tends to pool and run slowly downstream. When a river narrows, the water is forced to flow much more quickly through the smaller space — if you've ever been rafting, think about where the swiftest rapids are found (Answer: where the river is the narrowest!).

Autonomic dysfunction is real. You can beat it.

Think of a blood vessel as a river. . .

When a river is wide, the water in it tends to pool and run slowly downstream. . .

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

Your body has three mechanisms that work together to control how narrow or wide your blood vessels are. Seratonin (SSRI), beta (ß), and alpha (α) signals tell the muscles to tighten or relax in order to balance the rate at which blood flows through your veins.

Sometimes medications that work to either suppress or encourage these signals are prescribed in order to regulate the signals and ensure that blood returns to your heart.

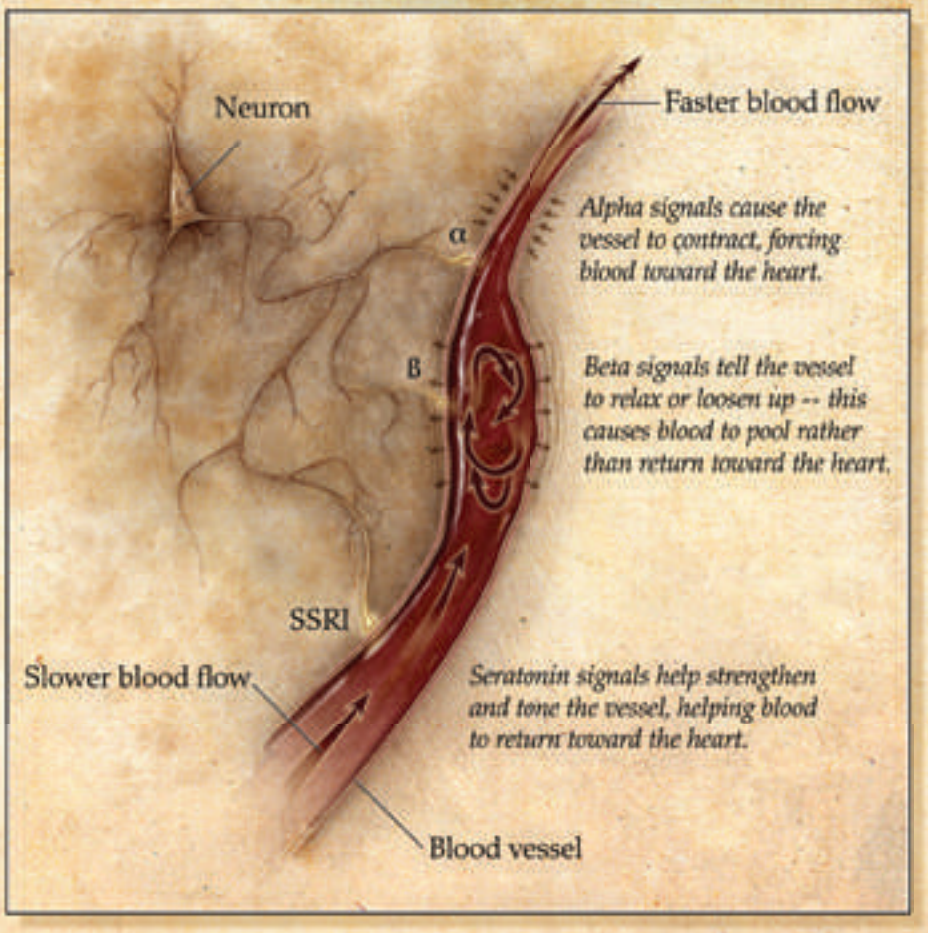


Figure 1. Signaling in autonomic dysfunction

Symptoms

If your autonomic nervous system isn't doing its job, you may experience some of the symptoms of autonomic dysfunction because the right amount of blood isn't going where it should.

A common symptom of autonomic dysfunction is dizziness and a fast heartbeat — especially when you stand up (Figure 2).

Because these symptoms can be seen in other conditions, people who have autonomic dysfunction may have a lot of tests or see many doctors before getting diagnosed.

"In addition to feeling sick, having stomach cramps and being really tired, I started feeling a lot of anxiety and frustration. I didn't know how to handle feeling so bad."

Common symptoms of autonomic dysfunction

You might have some (a few or many) of these symptoms:

- Dizziness/light-headedness
- Fainting
- Fatigue (being tired all the time)
- Headaches
- Stomach pains or cramps
- Nausea
- Difficulty concentrating or "Brain fog"
- Vision changes or loss of vision
- Feelings of hot or cold
- Lots of sweating
- Flushing
- 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

Who gets autonomic dysfunction?

Anybody can get autonomic dysfunction, but it's more common in:

- Caucasians
- High achievers (successful in school, athletics, etc.)
- Females
- People who are flexible or double jointed

Autonomic dysfunction can occur at any age. For teens, it is often within a year of starting puberty.

Teens can often connect their symptoms with a specific event or trigger:

- Acute illness such as a respiratory infection (cold virus), intestinal viral infection, or "mono" or a "mono-like" infection
- Injury
- Major surgery or a stay in the hospital
- Weight loss

"I think my biggest symptoms were dizziness and vomiting. I had…difficulty with vomiting and getting food down. I would get sick every time I ate. And even when I didn't eat, my stomach would really hurt. I also was very exhausted. I was dizzy and had blackouts. I was sleeping a lot. I didn't have any energy."



Figure 2. Dizziness and a fast heartbeat are common symptoms of autonomic dysfunction.

Will I Get Better?

The GOOD NEWS is that most teens recover from autonomic dysfunction and return to normal health.

In fact, there are specific things you can do that may help you feel better more quickly.

Of course, it won't always be easy. And it's going to take some time to get better...

but you're not alone.

Many teens experience symptoms of autonomic dysfunction. And many teens have been able to control their symptoms by working with their health care team to create a recovery plan and sticking to it.

You can beat autonomic dysfunction.

By committing to a recovery plan, you can focus your energy on getting your life back.



"I feel like I'm doing a lot better... and I really think it has to do with my attitude and my spirit.

At first, I wanted to just wake up one day and be completely better. But...that wasn't gonna happen.

So I decided to fight it."

What can I do to feel better?

Even if you feel terrible, **it's important** that you take STEPS to function. REALLY!!

Making the following **S T E P S** the center of your recovery plan can put you on the road to recovery.

S **Salt.** Add as much salt as your taste buds can tolerate to everything. This can be any kind of salt – table salt, sea salt, garlic salt, onion salt, seasoned salt, etc.

T **Take in large amounts of fluids** (3-4 liters every day). Recommended fluids include water, Pedialyte™, Gatorade™, Powerade™, Propel™, milk, juices, soups. Non-caffeinated beverages are preferable. You should pass colorless urine all day (at least four times).

E **Exercise regularly.** Make it a goal to develop an exercise program with the help of your health care team. 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. It's also important to do strengthening exercises every day.

P **Prescription medications.** Take medications as directed. Don't stop taking any medication without talking to your doctor, even if you feel better.

S **Support system.** This is important! Stay involved with your family, friends, psychologist, and others you can turn to for support.

Sleep. Get at least nine hours of sleep each night. Avoid naps.

School. Set up a plan with your family and teachers to return to school if you are not attending currently.

Set priorities and goals. Autonomic dysfunction is a medical condition. Prioritize your activities so that you use your energy in ways that help you stick to your recovery plan.

Safety. Do not do activities where you are at risk for falling as you cannot predict when you might get lightheaded or dizzy and pass out.

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

Why STEPS can help

Read on to discover the details of why making S T E P S a part of your recovery plan can put you in control!

S T E P S

Salt and Taking in Fluids

The power of salt and fluid

Taking in extra fluids pumps up the volume in your blood vessels and increases blood flow, which improves your circulation. This helps prevent dizziness and lightheadedness and helps regulate your body temperature.

However, if you just increase fluids without adding salt…you'll spend most of your day in the restroom! Salt helps your body retain the extra fluid, so the key is to take in as much salt as your taste buds can tolerate.

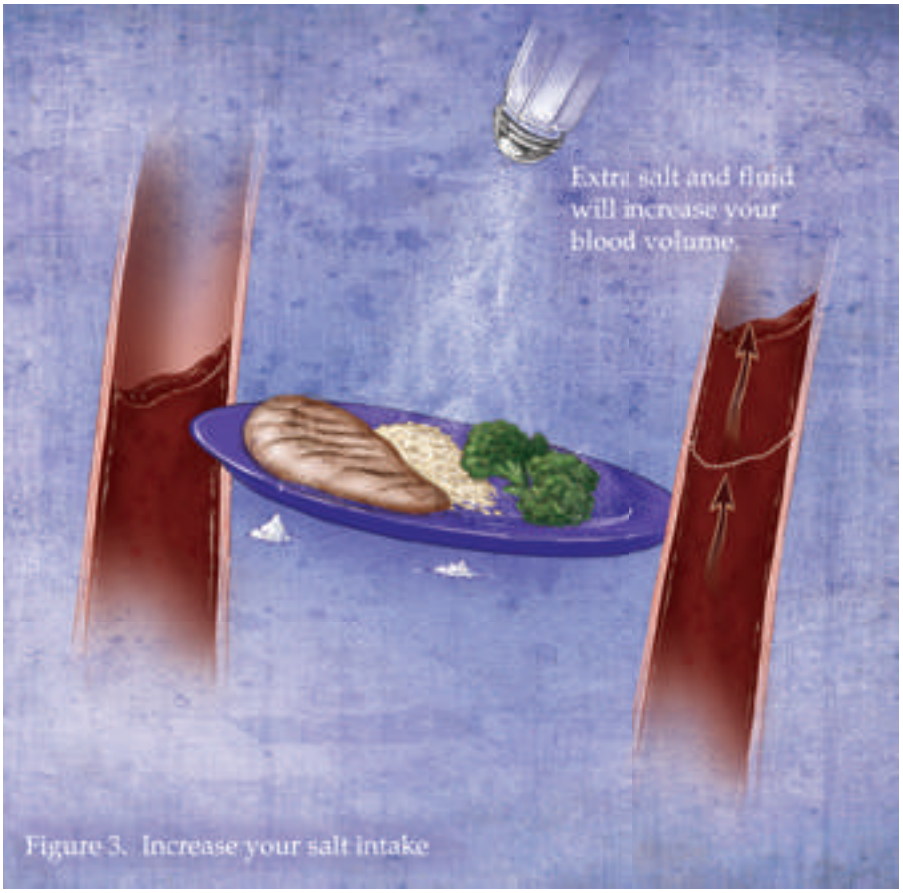


Figure 3. Increase your salt intake

Make it a goal

Make it a goal to drink 3 to 4 liters of non-caffeinated fluid every day (caffeine is a diuretic, which means it pulls water out of your body). That's equal to about twelve to sixteen 8-ounce glasses a day…or six to eight 16-ounce bottles a day.

Some beverages have a lot of salt in them. These are mostly sports beverages such as Gatorade™, Powerade™, and Propel™. Drinking salty beverages lets you get both salt and fluids in one shot.

Make it a goal to up your salt intake. Drink salty fluids. Add salt to your meals. Eat salty snacks like

- pretzels
- pickles
- cheese and crackers
- pumpkin seeds

Incorporate salty foods like pizza and Chinese food into a healthy diet.



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

Don't forget to brush... if you drink a lot of sugary liquids be sure to brush your teeth often.

Beware of empty calories in the beverages you drink!

Sugar-free liquids can help you get the fluids you need without added calories.

TIP

If you feel dizzy when you get out of bed, try drinking 8 ounces of salty fluids 15 to 20 minutes before you get up.

STEPS

Exercise, exercise, exercise

It may be hard to believe. How could exercise make you feel better?

In fact, exercise is another powerful weapon against autonomic dysfunction.

Ideally, you want to do two types of exercise on most days of the week:

- strengthening exercises, which focus on certain muscle groups, deliver an energy surge to get your blood flowing
- aerobic exercise, which elevates your heart rate over a sustained period of time, conditions your body for the long run



Exercise causes your body to release endorphins that can lift your spirit.

Exercise strengthens muscles, revs up your heart, increases circulation, and energizes your body.

TIP

Avoid exercise close to bedtime, as it can keep you awake.



Strengthening exercises

Do 25 repetitions of each of the following exercises each day.

Try to do these exercises when you are at your low point for the day in terms of how you feel. **Think of strengthening exercises as a jump start for your body.** For example, if mornings are the toughest for you, incorporate these exercises into your morning routine.

BEFORE YOU START your strengthening exercises, drink 8 ounces of a salty fluid (Gatorade™, Powerade™, or Propel™). This may help prevent feelings of dizziness as you exercise.

If any of these exercises cause you pain or discomfort, tell your doctor or physical therapist so your exercises can be adjusted.

- **Toe raises.** Stand with your hands at your sides and your feet slightly apart. Rise up on the balls of your feet. Hold for a second. Return to starting position. Repeat 25 times. (You can do these holding 3 to 5-pound weights if you choose.)

- **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 a second. Return to starting position. Repeat about 10 times if you are able. Gradually increase your repetitions until you can do three set of ten. (You can do squats with your back against a wall or door. Make sure you can see your toes sticking out beyond your knees when you do these.)

- **Biceps curls with 3- to 5-pound weights.** Stand with your feet shoulder-width apart. Hold weights at your side, palms facing out, elbows slightly bent. Keep your abs tight and your back straight. Slowly raises the weights toward your collar bones. Stop before you fully flex your elbows. Keep your wrists straight. Slowly lower the weights to the starting position. Repeat 10 times and build up to 3 sets of 10.

Strengthening exercises not only help you build muscle,
but they increase your circulation by giving groups of muscles a focused work out.

This workout focuses on your major muscle groups, which helps stop blood from pooling in your hands and feet and **gets your blood going to the places you need it!**

what counts as aerobic exercise?

Anything that raises your heart rate for a sustained period of time. A few examples:

Walking

Biking

Dancing

Skating

Jogging

Playing soccer

Hiking

Aerobic exercise

Start doing aerobic exercise in small amounts if that is all you can do. Work to increase the amount of time you exercise.

Aim for some exercise every day — even on a bad day.

For many teens, aerobic exercise is the **KEY** to recovery!

Set an exercise goal

Making a commitment to fit in aerobic exercise every day can seem difficult at first—especially if you aren't used to exercising.

YOU CAN DO IT...

by going slowly and not giving up.

TIP

Don't layer your clothing. Too many layers can cause your blood vessels to relax—which can make you feel dizzy or lightheaded.

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

"We started walking around the block, as far as we could make it. And that took a very long time… And now I'm at the point where I can run four miles at a time…It's taken a lot to work up to where I am now. But I think it's totally worth it that I can live a normal life."

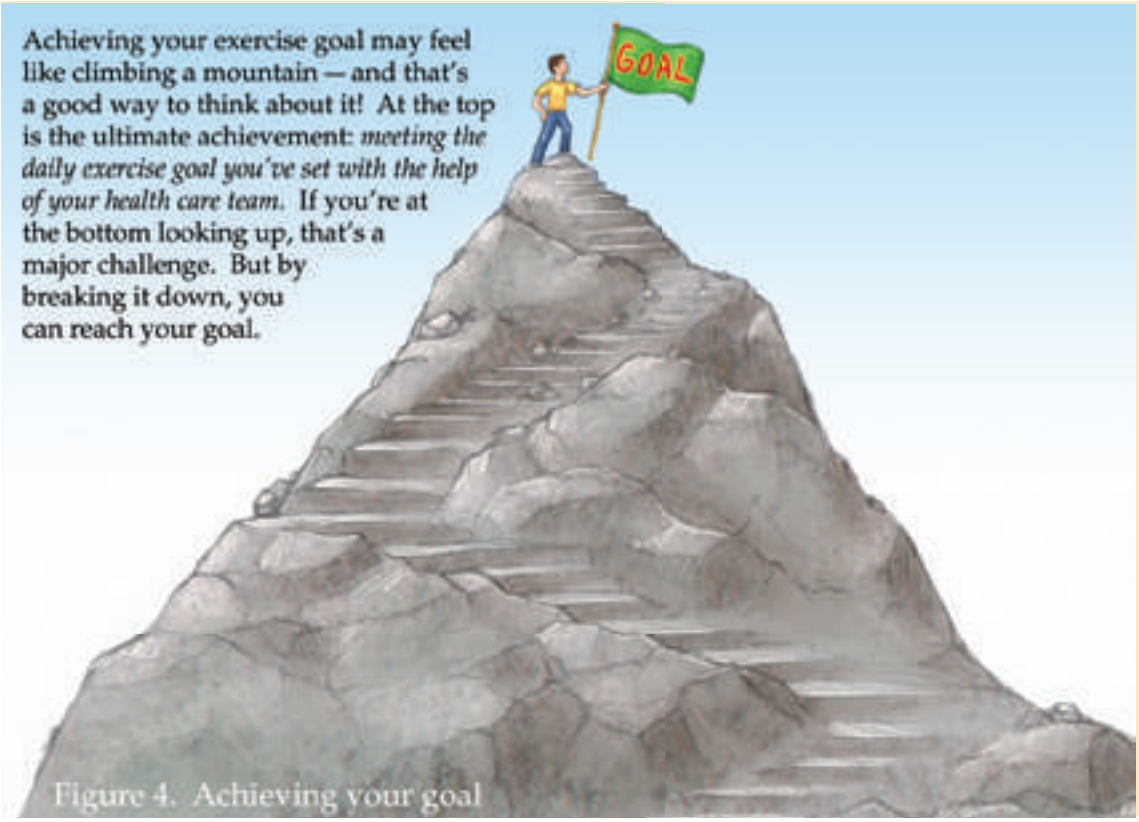
YOUR GOAL

If you're at the bottom looking up, that's a major challenge. But by breaking it down, you can reach your goal. **Start where you are.**

If it's on the bottom, fine.

Half-way up, fine.

Build from there.



Achieving your exercise goal may feel like climbing a mountain — and that's a good way to think about it! At the top is the ultimate achievement: *meeting the daily exercise goal you've set with the help of your health care team.* If you're at the bottom looking up, that's a major challenge. But by breaking it down, you can reach your goal.

Figure 4. Achieving your goal

Pace yourself

Focus on increasing gradually to reach your goal.

If you do too much because you feel good one day, you may pay for it the next.

If you can do 5 minutes, great. Take a brisk walk for five minutes. Time yourself. The next day, add a minute or two. Slowly increase the time you walk until you reach your goal.

If there are days you can't increase, don't worry about it. Do what you can every day. And don't overdo. This is really one of those times where SLOW & STEADY wins the race!

Each day you stick to your exercise plan will bring you one day closer to your goal of **getting your life back.**

S T E P S

Prescription medications

Medicines can't cure autonomic dysfunction, but they may help with your symptoms:

- Some medicines (alpha-adrenergic) tell your blood vessels to tighten up, which may improve your circulation.
- Beta-blocker medicines tell your blood vessels when to tighten and when to relax. These medications may prevent your heart from racing.
- Drugs affecting the serotonin level can help moderate some body responses and may potentially lessen feelings of dizziness and weakness.

Take all medications exactly as they are prescribed, and let your doctor know about any side effect right away.



"I didn't want to take medication. I didn't want people thinking I was weird, taking it out at meals… But after I found what worked for me, I just really feel like I can do so much more."

STEPS

Support system

A good support system is very important.

You know that what you are feeling is real, even if others may not think you look "sick." But others might not understand what you're going through.

Figure out how much you want to tell them about your condition and practice telling your story with your parents. Explaining your illness briefly is probably all your friends need. You may find them more supportive than you expect if you talk about how you're feeling.

Even if your friends are supportive, it may be tough to stay in touch if you can't participate in your normal activities. If you don't feel up to going out, invite your friends to your house for pizza and a movie.

In addition to counting on family and friends to be there when you need them, consider seeing a psychologist. He or she may be able to:

- Motivate you to follow your plan
- Teach you techniques for managing pain and fatigue
- Help you return to a more active lifestyle



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

"It's been really nice seeing a psychologist. I've been able to vent to her about the different things going on in my life. My anxiety level has definitely gone down!"

Most teenagers need between **8½ and 9½ hours** of sleep each night to feel rested.

Plan to get enough sleep each night.

Catch your ZZZZZ's

Getting a good night's sleep isn't always easy, especially for teenagers. Changes in your body clock, a jam-packed schedule and a 24/7 lifestyle can combine to undermine healthy sleep.

For teens with autonomic dysfunction, getting a good night's sleep is even more important. In fact, it is one of the keys to recovery.

Healthy sleep is vital to your well being, as important as food and water. It helps you think, feel and look better, as well as perform better in school and sports. And it only makes sense that your fatigue level will go down and your energy level will go up if you work sleep into your schedule.

Plan for 8½ to 9½ hours each night, and try to stick to a regular sleep schedule. Sleeping in for an hour or so on the weekend is fine, but if you sleep the morning away, it will be much harder to fall asleep at night…and much harder to get up on Monday!

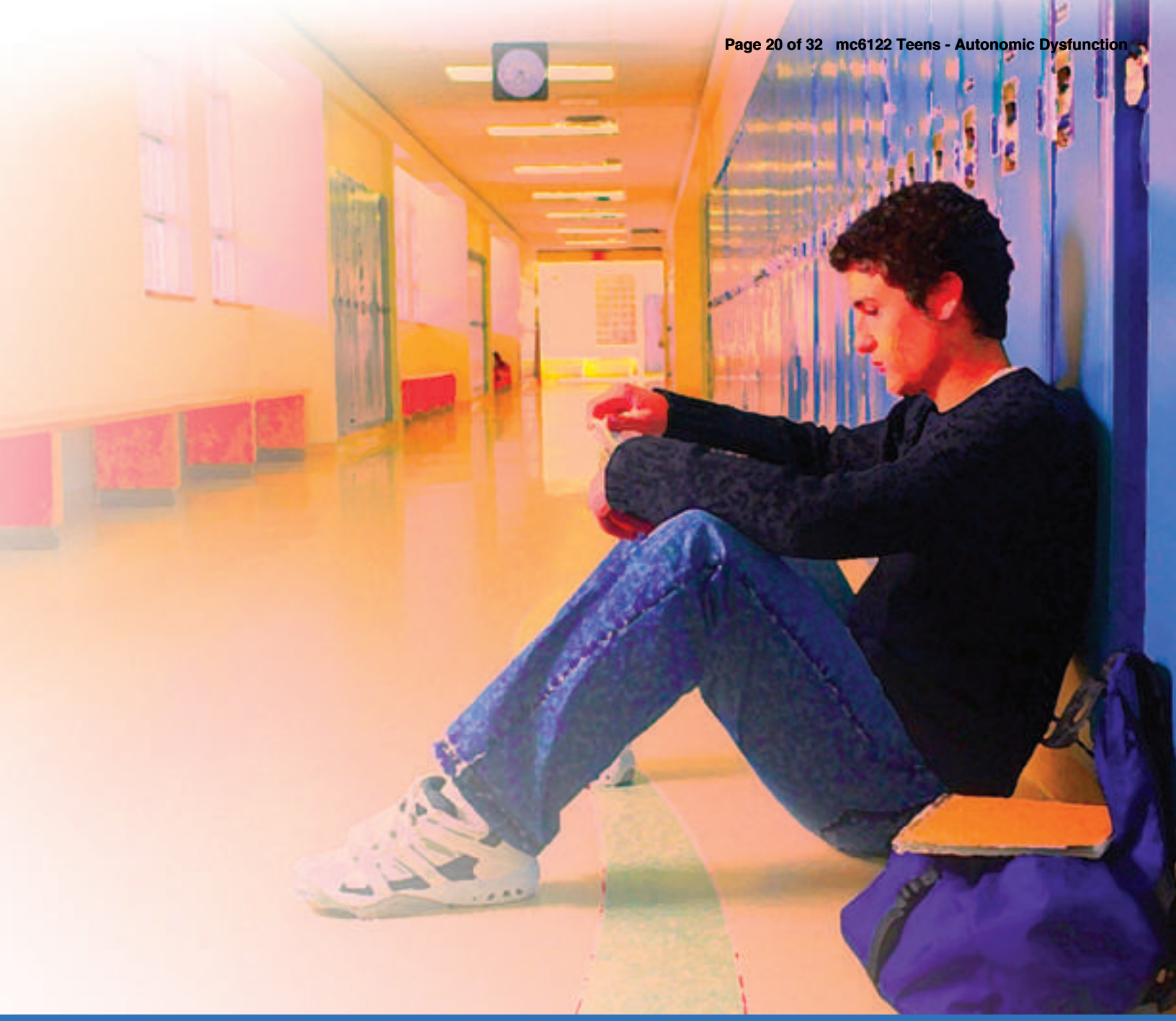
The "No Nap" rule. As a rule, save naps for those rare occasions when you will be up late. And even then, limit naps to no more than 45 minutes.

"A nap can be a lifesaver...but I know I need to save it for a very special occasion. The last time I took a nap was on the day of the prom. It was well worth it!"



Tips for good sleep

- **Stay away from pop,** sugar and big meals two to three hours before you go to bed.
- **Skip the caffeine** two to three hours before bedtime.
- **Exercise.** Daily exercise will help you sleep (do it at least two hours before bedtime).
- **Clear your mind.** Several hours before bedtime, write down things that are on your mind or tasks you need to do.
- **Make a bedtime routine.** Doing the same things each night before you go to bed will give your body the signal that it's time to sleep.
- **After 9 p.m., focus on calming activities.** Avoid video games and violent or scary TV shows, movies or books.
- **Don't nap during the day.** Naps do more to mess up your sleep cycle than they do to help you catch up on your sleep.



6 tips
for staying in school on a rough day

1. Slow down. Take a moment to relax and release the tension from your body using relaxed breathing. Focus your energy on your goal of getting your life back. You made it to school, and the best thing you can do 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. Go back to class as soon as you can.

2. Prioritize. When you're very fatigued or in a lot of pain, focus on the things you really need to do, and do them. Skip activities that aren't critical.

3. Revise your expectations. Even if you're having a hard time concentrating, or you're worried because you can't do as well as you'd like, remember that your goal is simply to stay at school and do the best you can.

4. Call in reinforcements. Tell a trusted friend or teacher that you're having a rough day. Ask them to help you relax and distract your attention.

5. Stay positive. Focus on what's going right in your life, rather than your pain or fatigue. Remind yourself that you've made it through tough days before, and you can do it again. Tell yourself that it will get better — because it will!

6. Plan ahead. It's hard to figure out what you're going to do on a difficult day when you're in the middle of it. Before a tough day hits, decide what you'll do when things get bad, where you can go to relax and who you can talk to. Tell your support people ahead of time that you'd like their help, so they won't be surprised when you ask for assistance.

When to stay home

So, when should you bag it and stay home? When should you go home if you're at school? If you're having any of the following symptoms, stick close to home. Otherwise, try going to school or staying at school. You may feel better once you get into the routine of your day.

- A temperature of 100.4 degrees Fahrenheit (38 degrees Celsius) or higher
- Vomiting
- Diarrhea

Getting Your Life Back

It's all about balance

You know it's going to take hard work to get your life back. You're going to have to push your body to do things it doesn't want to do.



But you can do it.

"Everything in moderation. I think that's what I really struggle with because I wanna do everything!"

By focusing your energy on beating autonomic dysfunction, you can begin to take back your life.

The first step is to prioritize. Focus on the things you need to do. By deciding what's really important, you can better choose how to spend your time and energy — and you can let go of those things that don't make the cut.

Think about how you are going to balance those things throughout your day. Take into account when your energy level is at its peak or at its lowest. **Give yourself a break when you need one...but then tackle a goal!**

Make a plan that you can live with.

And, when the going gets tough, don't be shy about asking for help.

"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."



TIP

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

"At first, I was so 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 recovery plan – even when it's hard – is my secret weapon."

5 tips for getting your life back on track

1 **Prioritize.** Focus on the things you need to do to get well, and do them. Skip activities that aren't critical.

2 **Revise your expectations.** Even if you feel exhausted or you're worried because you don't think you'll be able to do as well as you'd like, remember that your goal is to do the best you can. Adjust your schedule if you have to, but don't give up!

3 **Call in the reinforcements.** Tell those you trust about your plan to feel better…and let them know when you're having a rough day. Ask a friend to walk with you if you don't think you can exercise, or ask if you can skip chores so you can get your homework done. Talk to a counselor or psychologist about your feelings of frustration or anxiety.

4 **Stay positive.** Don't dwell on your symptoms. Remind yourself that you've made it through tough days before, and you can do it again. Tell yourself it will get better – because it will!

5 **Plan ahead.** It's hard to figure out what you're going to do on a difficult day when you're in the middle of it. Before a tough day hits, decide what you'll do when your symptoms get bad, where you can make adjustments to your schedule, and who you can talk to.

Make a plan and stick to it

Write down what you're going to do each day to take back your life.

Include things like

- what time you're going to get up in the morning
- when you're going to exercise
- your school and homework schedule
- when you're going to make time for relaxation and fun
- when you're going to bed



Do.



Don't over do!

Share your schedule with your parents, and ask them to help you stick to it even when it's hard.





It's all about BALANCE

- ✓ Exercise
- ✓ Eat right
- ✓ Take meds
- ✓ Relax
- ✓ Do school
- ✓ Have some fun
- ✓ Hang with friends
- ✓ Laugh

TIP

Let yourself sleep in an hour or so on the weekend…but changing your sleep schedule more than that can make it harder to get up on Monday.

TIP

Keep it cool…Don't take hot showers or baths. Hot water can cause your blood vessels to relax—which can make you feel dizzy or lightheaded.

Conclusion

Living with autonomic dysfunction isn't easy. By making a plan to get your life back, you are one step closer to your goal of getting well.

And every day that you stick to your plan, you are another step closer.



There will be peaks and valleys that you will need to deal with—maybe even on a daily basis—but you can do it.

Some teens say that dealing with their symptoms feels like climbing a mountain…and the key is to keep climbing!

Slow and steady is winning!

You can beat autonomic dysfunction.

And your health care team is here to help. If you have any questions regarding your treatment plan or your symptoms, talk to a member of your health care team.

"When I decided I was going to fight my symptoms, I was scared. My first day following my plan felt like boot camp. But my mom and dad helped me stick to it. Today my life is way better than it used to be."

Focus on the "3 C's"

Coping

What you are feeling is real, even if you don't look sick. But others might not understand what you're going through. Explain autonomic dysfunction to those who count — your family, close friends and other trusted adults. They are your first line of support.

Spend time with friends. **Laugh.** Humor really is therapeutic.

Use strategies like relaxed breathing or guided imagery — or relax with your favorite playlist — to calm you when you're stressed.

See a counselor or other health professional to address issues of anxiety, frustration and depression.

Controlling

Focus on your treatment goals. Get enough salt and fluids; don't skip meals; stick to your exercise plan; keep a regular sleep schedule and don't nap during the day; don't overdo it; go to school and maintain a regular schedule while working through your symptoms.

Curing

While there is no easy "cure" for autonomic dysfunction — you can't take a pill and feel better — you can stick to your recovery plan…even when you feel like you can't.

In the long run, **exercise, exercise, exercise — and time and patience — is at the heart of beating autonomic dysfunction.**

My plan to beat autonomic dysfunction

Plan your typical day. Be sure to include time for exercise, relaxation, and, of course, those things that you have to do, like homework and chores.

Weekday Schedule

Weekend Schedule

Log

Keep track of your goals and accomplishments! Post this log where you will see it every day to keep you on track with your recovery strategy.

	Goal	My Plan	How I did
Salt			
Fluid			
Exercise			
Medications			
Sleep			
School			
Other			

Resources

Ask your doctor or nurse about where you can find reliable information about autonomic dysfunction.

BARBARA WOODWARD LIPS PATIENT EDUCATION CENTER

Mrs. Lips, a resident of San Antonio, Texas, was a loyal patient of Mayo Clinic for more than 40 years. She was a self-made business leader who significantly expanded her family's activities in oil, gas and ranching, even as she assembled a museum-quality collection of antiques and fine art. She was best known by Mayo staff for her patient advocacy and support.

Upon her death in 1995, Mrs. Lips paid the ultimate compliment by leaving her entire estate to Mayo Clinic. Mrs. Lips had a profound appreciation for the care she received at 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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