

Section B: Living with Dysautonomias

Living with Dysautonomias

Living successfully with a *dysautonomia* requires understanding how your body’s “automatic nervous system” (*autonomic nervous system*) functions, and how changes in *autonomic nervous system* function may cause your symptoms. The first section of this book covers these topics. Living successfully with a *dysautonomia* also requires understanding how chronic illness impacts the patients, caregivers, and family, at home, at school, and at work—and requires important changes in lifestyle. This section of the manual gives you practical guidance for living successfully with *dysautonomias*.

Because causes of *dysautonomias* are not well understood, and because there are many forms of *dysautonomia*, your doctor and you will likely spend a lot of time trying to find reversible causes and devising a treatment program. For this reason, your relationship with your physician is crucial. We have included some suggestions on working with your doctor.

The changes that you and your family may face can place new emotional burdens on all members of the family. The following chapters include information on coping

strategies, caregiving, finding or starting a support group, and the issue of children with a *dysautonomia*. Finally, having a chronic illness is likely to lead to inquiries about benefits that may be available from the insurance portion of Social Security. A summary of benefits is included, to help you understand your rights under this program.

Finding and Working with a Physician

Despite that fact that *dysautonomias* affect over a million Americans, you will probably find that very few people and even **few doctors have heard of *dysautonomias***. It is likely that few if any doctors in your area specialize in treating autonomic disorders.

Few doctors have heard of dysautonomias.

Researchers over the last few years have brought to awareness the large number of people who are affected. Dr. David Robertson, of the Autonomic Dysfunction Center at Vanderbilt University, has called this awakening an “*epidemic of disease recognition.*” With growing awareness, these disorders should become easier to recognize and treat.

It can be frustrating learning to live with a condition that others have never heard of, let alone try to pronounce (An easy way to remember it is to sound it out like this: **Dis** - like in distant, **auto** – like the car, **NO**- like what we tell our kids, **mia**- like Mia Farrow:

Dys—auto—NO-mia). The medical terminology can also be confusing. **The same basic set of symptoms can be called by a variety of names.** For example, symptoms of a long-term inability to tolerate standing up—*chronic orthostatic intolerance*—have been labeled as “*POTS*” (*Postural Orthostatic Tachycardia Syndrome*, or *Postural Tachycardia Syndrome*), “*COI*” (*Chronic Orthostatic Intolerance*), *Mitral Valve Prolapse-Dysautonomia Syndrome*, *Neurocirculatory Asthenia*, *Soldier’s Heart*, *Neurally Mediated Hypotension*, and other names in a long list. It is no wonder that many patients feel frustrated and confused.

Finding a physician able to diagnose, treat, and follow your *dysautonomia* will likely take **effort on your part**. Unlike diseases or conditions that affect only one part of our body, *dysautonomias* can affect every part and system of our body. The *autonomic nervous system* plays a variety of roles in regulating many “automatic” functions, such as breathing, blood pressure, heart rate, digestion, sexual function, and other activities. Because of this, it is often difficult to determine which type of physician should manage the condition.

Your care may require some extra **effort by your doctor**. Since the cause of your symptoms may not be well understood, developing an effective treatment plan may take time. People with *dysautonomias* must be both patient and persistent. Because of large differences among patients, and continuing mystery about mechanisms of *dysautonomias*, doctors need to learn from their patients about what works and what doesn’t.

Your first priority should be to **find a physician willing to work *with* you.** Whether that physician is a cardiologist, neurologist, endocrinologist, psychiatrist, internist, or family practitioner is less important than his or her ability to work with you and other physicians on your behalf.

Find a doctor who will work with you.

You and Your Doctor: A Working Relationship

Because little is known about underlying mechanisms of many forms of *dysautonomia*, **your physician will probably have the task of treating your symptoms without really knowing their exact cause.** For this reason, much of what will be done will be through a trial and error approach. Both you and your physician will need to have an understanding that finding a program that works will require time, patience, and open and honest communication. Your relationship and ability to communicate with your doctor will make a big difference in putting together an effective therapy program.

Your **symptoms are likely to change** over time. Keep your doctor informed about how you are doing and about changes you notice. For instance, a particular medication might you feel better in one way but worse in another. Your doctor might be able to change your prescription or

start you on another drug that would work the same way but with fewer side effects. If you notice major improvements, you should inform your doctor. It's possible you may not need as much medication to manage the problem.

Keep your doctor informed.

You should develop a plan with your doctor about **symptoms that require immediate attention** and those that can wait for a return visit. A brief discussion about this will help give you peace of mind when your symptoms are of concern.

Talking with a physician about multiple symptoms can be a problem, if you've had unpleasant interactions at office visits in the past. You might be concerned about what the doctor might think: "What if they think I'm CRAZY?" Don't let this concern keep you from relaying everything the doctor needs to know. You can't expect your physician to put the puzzle together if you keep out half the pieces. **Tell your physician about all your symptoms.** Let your doctor decide what is important information.

Create a bullet list of questions to ask. Many of us forget our questions unless we write them down. Keep in mind that your doctor has limited time to discuss your condition and treatment. Before visiting your doctor, ask yourself, "If I could improve one symptom, which would it be?" This type of thought process will give you and

your physician a better opportunity to work on the symptoms that cause you the most trouble.

You may want to consider having a **family member or friend go with you**. Having someone with you may make you feel more comfortable, and a family member or friend can also give your physician details you may not recall.

Keeping a **daily journal** can also be a useful tool, both for you and your doctor. This may allow your doctor an opportunity to diagnose your condition and see trends or patterns in your symptoms. You might include blood pressure, pulse rate, body weight, and the timing and circumstances of events that trigger symptoms, mood, activity—even thoughts. Talk to your doctor about information to record. A one-month journal is usually adequate to give a picture. Let your doctor review your journal, since what may seem insignificant to you may be significant to your doctor. Keep in mind the nature of *dysautonomias*, in which symptoms often have peaks and valleys. Many women notice major changes while ovulating or having their period. You may notice changes if you become dehydrated, distressed, too warm, or even with a change in the weather. Keep track of your fluid and salt intake. Note whether resting in a recliner and reading a good book or magazine helps, and whether stimulation such as the radio, video games, or television makes a difference.

If your doctor starts you on a new medication, it is important to **discuss potential side effects**. You may

want to purchase a reference source on prescription medication, such as the Family PDR. This manual lists the names of medications, their use, and side effects. It is helpful to know side effects triggered by your medication and not your condition.

Referral to an Autonomic Specialist

Physicians in several fields of medicine specialize in *dysautonomias*. Testing in a **specialized autonomic function testing laboratory** can help identify what form of autonomic involvement you have and speed development of an effective therapy program.

Consider specialized testing.

You should not feel reluctant to talk to your physician about going to another facility for testing. You will likely find that your physician will actually encourage you to visit one of these facilities, because the visit may provide valuable and otherwise unobtainable information that your doctor can use to help you.

Keep in mind that there are **relatively few autonomic function experts and testing laboratories**. For a list of physicians and facilities in your area, try visiting the website of the National Dysautonomia Research Foundation, www.ndrf.org, or give the Foundation a call at 651-267-0525.

Research Facilities - Should I Participate in a Study?

Many people who contact the NDRF ask about participation in research studies. There are a limited number of centers in the United States that conduct research on the *autonomic nervous system*. Patients are recruited to participate in these research studies, also known as “protocols”. Each protocol has specific criteria for participation. For a list of ongoing studies you can contact the NDRF or visit the National Institutes of Health’s Clinical Trial web site at: (www.clinicaltrials.gov).

Participation in a research study may help; however, it is important that you investigate the study thoroughly and review the consent information prior to participation.

Some **benefits of participating in research** are:

- You see physicians who specialize in this area of medicine. What may be unusual for your local physician may be routine for the physician conducting the research.
- You have the opportunity to learn more about what may be causing your symptoms. The testing could reveal important information about your condition that may not be available to your personal doctor.
- The medical institution typically covers the costs of the research testing, which otherwise would be

expensive if available at all.

- You help researchers understand the illness better, making it possible for them to devise sensible treatment plans and even look for new possible cures.

If you decide to participate in a study, keep in mind some of the possible **limitations of the research:**

- You may be required to stop taking your medications, for the doctors to see how you function without them.
- You may have to pay for travel.
- Some tests can be painful, uncomfortable, or not directly related to your problem.
- You may have to spend several days in the hospital.
- You may need pre-certification from your insurance company. Testing at the research facility to confirm your diagnosis prior to the start of the study may have to be paid for through your medical insurance.
- You have to meet the criteria for participation in the study. Not everyone qualifies, and research patients may not be recruited once a quota is filled.
- Most important, you should understand that the usual primary focus of a research study is not to help a

single patient but to learn more about the condition in general and how to treat it. Research studies therefore may not provide for long-term care or follow-up. This means that you will likely be returning to the care of your personal physician after participating in the research. Nevertheless, the researcher and the study results may help you and your doctor gain more knowledge about your condition and help devise an effective therapy program.

Physicians conducting research should not take the place of your local physician.

The research might give you immediate results, but alternatively it might take several months or even years before the research is completed and the results fully analyzed. You should have a clear understanding of what type of feedback to expect prior to your participation.

Keep educated about your condition. Passing along new information will help both you and your doctor. You will find that most physicians appreciate information provided them, especially if from a reliable source. Resource tools available today allow you a tremendous opportunity to stay abreast of new discoveries. You can find updates from a variety of sources, including the NDRF website, patient conferences, books, and newsletters. The National Library of Medicine's websites offer you easy access to medical search engines that can also help keep you informed of new research discoveries. Become your own advocate for improving your health!

Day by Day with Dysautonomia

This chapter stresses the importance of living with *dysautonomias* day by day. We thank Dr. Lisa Benrud-Larson, of the Mayo Clinic in Rochester, Minnesota, for her assistance.

Much of the information in this chapter comes from two sources; both are wonderful resources for individuals trying to learn how to cope with a chronic medical condition:

- *Taking Charge: How to Master the Eight Most Common Fears of Long-Term Illness.* Pollin R, Golant SK. Random House, 1994.
- *Living Well with a Hidden Disability.* Taylor S, Epstein R. New Harbinger Publications, Inc., 1999.

Additional material on chronic illness can also be found at the Mayo Clinic Internet site: <http://mayoclinic.com>

Chronic Illnesses

We are all familiar with acute illnesses such as the flu, strep throat, and pneumonia. They are generally treatable,

have an identifiable cause, last a relatively short time, and involve a return to normal health.

In contrast, chronic illnesses, such as *dysautonomias*, chronic pain, or diabetes, can continue indefinitely. Their course can be affected by multiple factors, including heredity, environment, and lifestyle. Consequently, living with a chronic illness can be a continuous challenge, marked by many ups, downs, and unexpected turns.

Living with a chronic illness is a continuous challenge.

Accepting Your Disorder

With an acute illness, you know you eventually will feel normal again. When you have a chronic illness, there often is no cure in the traditional sense. You may never return to your “normal” way of life. Adaptation and acceptance therefore become important in maintaining your quality of life.

The first step to accepting your condition is to understand it. Knowing the “details” (e.g., common symptoms) can alleviate uncertainty and help you learn how to manage life with a *dysautonomia*. Your physician or health care provider and the NDRF can help you with this.

Understand your condition.

As suggested earlier, a daily journal can be extremely helpful, giving you get a better idea of your day-to-day experiences.

Modifying Your Life

Coping successfully with a chronic illness requires significant lifestyle changes. Modifying your lifestyle to help you maintain as “normal” a life as possible can help you gain a sense of control over your illness, rather than feeling your illness controls you.

Pacing your activities is very important. You might have been able to work 8 hours and then do chores at home, and now doing so would put you in bed for a week! You need to learn how to pace your activities, take “baby steps.”

Making a **weekly chart of activities/tasks** that need to be done can help. Seeing things in black and white often helps in many ways. You might believe that you are not doing anything, yet when you actually make a list of your day-to-day activities, you may see you are trying to accomplish a great deal in one day or one week. The list can help you set priorities about tasks that definitely need

to be accomplished that day or can be put off or eliminated.

It can also help in decisions about how responsibility for certain tasks might be shared among family members. For example, your spouse might take over the grocery shopping, or you might do only one load of laundry on a particular day. Deciding on the right balance between overdoing it and doing too little is not an easy task. It will take time and a lot of trial and error.

Do things you enjoy. This can distract you from your illness. Focus on hobbies and activities you can still do and look for new ones to replace those you no longer can pursue. An example would be avoiding a noisy art show outdoors in the heat and instead visiting an art museum in the cool indoors.

Know your limitations. Substituting one activity for another may become necessary in maintaining a sense of well-being. For instance, instead of scuba diving, which is strenuous physically, you could try snorkeling.

Our son plays little league baseball. Recently he asked if I could go to his game. As much as I wanted to be there to show support, I knew that going wasn't the brightest idea. So we improvised – my husband took the camcorder and taped it. This allowed us to watch it as a family - indoors where it is cool, and where I could watch a few minutes at a time. Not to mention it allowed our son an opportunity to see where he could strengthen his game!

Take an inventory of your interests. People often forget about things they had an interest in but have not thought about for years. Maybe you loved to paint as a high school student. This may be a good opportunity to get back into it.

Daily Life Tactics

There are several **basic tips** to pace your life:

- Get adequate rest
- Eat and drink right.
- Try to keep a regular schedule.
- Get an appropriate amount of exercise, as prescribed by your physician.
- Don't get dehydrated.
- Stay on your medication routine.

Mornings can be a very rough time. Start slowly and use your knowledge to help give yourself an edge. A study showed that patients who drink water before getting out of bed in the morning did better than patients who did not drink water. If your physician has advised you to increase both fluids and salt, a glass of V8 or tomato juice might be even more helpful, as these drinks contain large amounts of sodium.

Exercise plays an important role in treating most chronic conditions, including *dysautonomias*. Staying in shape improves your sense of well-being.

The veins in the legs contain one-way valves that allow blood to flow towards your heart without allowing it to back up into the legs. Muscle surrounds deep veins in the legs and compresses these veins when you contract your leg muscles. **Muscle pumping** helps to keep blood moving towards the heart and upper body when we stand upright. You can do different types of exercise to assist your venous pump. A very simple routine such as flexing your feet with one or two pound ankle weights will get the pump going. You can also tighten your calf, thigh, and buttocks muscles. Talk to your physician about whether muscle pumping would be right for you.

Showering If you suffer from lightheadedness when you stand up (*orthostatic intolerance*), you might feel worse taking a hot shower in the morning. Many patients with *chronic orthostatic intolerance* have heat intolerance. Consider taking your shower prior to going to bed at night.

Treatment for Anxiety or Depression Chronic illness, and especially chronic illness from an abnormality of the function of the *autonomic nervous system*, can increase the susceptibility to anxiety, panic, and depression. There is nothing wrong with asking your doctor if you might benefit from a medication to help you cope.

Avoid triggers that worsen your condition. Some triggers to keep in mind are:

- Hot environment (e.g., hot shower, sauna, jacuzzi)

- *Dehydration* (not getting enough fluids)
- Emotional *distress*
- “Over-stimulation” (i.e., amusement parks, concerts, sporting events, video games)
- Large meals
- Alcohol
- Skipping medications

A ringing of a telephone can cause a “fight-or-flight” response. Turn the volume down!

Diet

Eating large meals tends to shunt blood toward the gut. This can also worsen *orthostatic intolerance* and make any *dysautonomia* patient feel sluggish, tired, and worn out, because less blood is delivered to the brain, heart and lungs. Try eating smaller meals, more often. A half bagel or English muffin or a small piece of fruit is a good way to start off the day. Sugary or starchy foods may also tend to make you more symptomatic.

During eating, you might try elevating your feet to heart level and exercise your legs, to keep the blood from pooling. Just flexing your feet back and forth can have a tremendous benefit.

The subject of what we eat is also very important. For many patients with *dysautonomias*, a diet high in salt and fluids is necessary, to maintain adequate blood pressure during standing. A half-cup of Campbell’s chicken

noodle soup has 890 mg of sodium. You should discuss salt intake with your doctor.

You might try avoiding foods high in sugar and starch. Some researchers have found that consumption of these substances can worsen symptoms. This is another matter to discuss with your doctor.

Environmental Temperature

Patients with *dysautonomia* can have intolerance to heat or cold. Our bodies have a built-in thermostat, and the *autonomic nervous system* is a key system the brain uses to regulate body temperature. It is therefore important to dress appropriately, as well as regulate the amount of time you expose yourself to heat or cold.

If you have heat intolerance and plan on being outdoors during the summer months, dress in cool and light clothes and remember to limit the amount of time you spend in the heat. Sitting under a tree might help to reduce the likelihood of heat exhaustion and yet still give you a chance to enjoy the outdoors. And force yourself to drink fluids.

Don't assume that your body has the capacity to warm itself when you are exposed to cold. Shivering is a natural response that our bodies have to keep warm. Just like sweating is a way to keep our body cool in the heat, shivering is a way the body stays warm in the cold. The nice thing about the cooler weather is the fact that you can always put on multiple layers, and cuddle up with a

warm blanket. Electric blankets during the cold winter months are wonderful. Setting the blanket on low 15 minutes before getting into bed will avoid the shock of getting into an ice-cold bed.

Compression Stockings/Abdominal Compression

Compression stockings can help those of us who suffer from blood pooling in the lower half of the body, due to a problem with the veins. If you do use compression stockings, it can take some time to take them on and off. You may find it easier to put your stockings on and off while lying in bed. Lying down will keep you from becoming symptomatic while taking them off! It's also helpful to use a small amount of baby power when putting them on. Compression stockings may be ineffective in preventing a fall in blood pressure standing, when the problem is an inability to constrict *arterioles*.

L'eggs makes a line of affordable pantyhose for people with varicose veins. I purchased two pairs one size smaller than what I would normally wear, and wore both of them at the same time. I found them to be fairly comfortable, and easy to take on and off. Keep in mind however that they do not last as long as the compression stockings. If you wear stockings only occasionally, this may be an effective and less expensive approach to take. Abdominal compression has also been used to help treat pooling. Again wearing a girdle one size smaller than what you are can make a tremendous difference in how you feel. The combination of girdle and stockings can

work well together. If wearing girdles or compression stockings isn't your style, try wearing bicycle pants.

Medic-Alert Bracelets

We recommend that patients with *dysautonomias* wear a Medic-Alert bracelet. This will speak on our behalf when we may not be in a position to speak for ourselves. The back of the bracelet can state "See wallet." Inside the wallet would be a piece of paper or laminated card about the condition, allergies and sensitivities to medications, names and phone numbers of physicians, and spouse or friend contact information. For information on obtaining a Medic-Alert bracelet, please visit their web site at <http://www.medicalert.com/> or call 888-633-4298.

Work

Whether or not you keep working is an individual decision affected by a number of different factors (e.g., severity of symptoms, type of work, financial situation). There are no straightforward rules here.

It is likely your ability to work will be affected in some way by your illness.

It may be that you can no longer put in 10-hour days. Perhaps you can no longer travel as part of your job. Maybe your job requires you to be on your feet all day, and that is just not possible any more.

If you want to continue to work, you might have to struggle with what, if anything, to tell your employer. Do you maintain your privacy, or let your employer know, so special accommodations can be arranged? This is a personal decision with no universal right or wrong answer. It may help to make a list of the pros and cons of disclosing your condition. Many things are going to affect your decision, including your specific work environment and job duties.

Work can involve episodes of emotional distress in healthy people, so it's no surprise that it can worsen physical symptoms in someone with a chronic illness. Just as you are going to have to make several lifestyle changes at home to manage your condition successfully, you're probably going to have to make changes at work. This might mean setting more limits. Where you used to skip that morning break and eat lunch at your desk, you may now need to take full advantage of the respite.

It can be scary and frustrating to have to "slow down" at work. You might be afraid of what will happen and what people will think of you. You have to remember that if you don't slow down, you may be jeopardizing your health, which in the long run will result in being able to do even less.

There may be a time when you have to discontinue working altogether. The decision to leave the work world, whether temporarily or permanently, can be

accompanied by a whole host of emotions, including anxiety, depression, guilt, or relief.

To minimize anxiety associated with leaving work, structure your day (e.g., read books, listen to music, take a course over the internet, talk with friends), and try to learn something new. Maybe check out a library book on sketching or sewing. Make a list of your positive traits, to help remind you that you are of value even if you're not working.

If you are contemplating taking time off from work, be sure to investigate all your options regarding possible assistance. See the section about the Family and Medical Leave Act and disability leave.

Travel

Driving is one of the most important aspects of our independence and a necessity in everyday life. Faced with the reality that driving may cause risk not only to ourselves but to others, we must ask ourselves, "Is it safe for me to drive?" Discuss driving with your doctor. Your doctor can help to determine if your condition puts you at risk. If you are not able to continue driving, you will have to find ways others can help with your travel needs. Besides family, friends, and neighbors, your community may have programs. Your local chamber of commerce or United Way can give you information about public transportation and other programs.

Wearing **sunglasses** when you travel can reduce stimulus overload. You may notice that your symptoms don't seem as intense when you travel in the evening than in the daytime. Wearing earplugs can also help reduce the impact.

Wear a **girdle or compression stockings** while traveling. Abdominal compression helps us to keep blood from pooling to the feet, legs and stomach. Have you ever noticed a change in your skin color when you stand upright? You may notice that your feet and legs change to a purplish/blue! Compression garments will help you to keep the blood in the upper extremities where it belongs.

For many patients with *dysautonomias*, **air travel** can be a nightmare. Should you fly? Again it's always best to discuss this with your physician. If your physician tells you it is all right for you to fly, discuss the following to see if they make sense for you:

- Drink extra fluids for at least a couple of days before departure.
- Eat a diet high in salt (chips, pretzels, beef jerky, pickles).
- Avoid stressful, stimulating situations the day before or of departure. For instance, avoid going to the mall for last-minute shopping.
- Wear compression stockings and an abdominal compression garment.
- Wear earplugs.
- Take a couple deep breaths before takeoff.

- Ask your doctor about a medication to calm you and enable you to sleep during the flight.
- Fly with someone who knows your disorder. This will help if you have problems during the flight.
- Request bulkhead seating, so you can elevate your feet to heart level during the flight.
- Request a wheelchair at your destination.
- Try to arrange a day of rest after your flight.

When to Ask for Help

It is not easy to find the right balance between independence and help. You may need assistance in a variety of areas. At different points, you may need practical, financial, emotional, or physical help. Asking for help is more difficult for some than for others.

We all need help from others, whether we're healthy or not.

People often feel guilty asking for help from family and friends. It might help to think about how things would be if the shoe were on the other foot. If your spouse or best friend had a chronic illness that required your assistance, would you resent a plea for help? Not likely!

Explaining exactly how someone can help can provide a sense of relief to the helper, who may not know what to do. You can make a list of the areas where you do and do not need assistance.

Don't assume that others can read your mind. You need to be clear in relating how you feel and what you need. Your friends, family, and caregivers need to do the same. This is not easy! You may not be sure of what you want. You may be afraid that you are asking too much or becoming a burden.

Social Activities

Staying involved in family and social activities as much as possible can help you cope with your illness. If you notice that these activities make your symptoms worse, then limit the time you spend on them. An example is a family picnic. If it is an all day function, plan on spending only an hour or two.

How do you tell your friends and family? How can you help them understand what you are going through? Obviously, you do not experience your illness in a vacuum. Those close to you are also significantly affected by your condition. They won't experience the same physical effects you do, but they will share other struggles (e.g., emotional, financial). This is a time of heightened stress and anxiety for the entire family.

Try to arrange a quiet time to sit down and talk with your family about issues related to your health. Explain clearly and speak directly. Ask if they understand what you're trying to say, and clarify what is not clear. Listen to what they have to say. Try to express yourself in a non-

threatening manner. Statements like “*Why do you always avoid me?*” will probably make your loved ones feel attacked and cause them to become defensive. Instead, try to phrase your statement in more neutral terms, such as, “Help me understand what you are going through. I feel like you don’t want to be around me anymore and that hurts me. I miss being around you.”

It is also important to give your loved ones permission for them to have their feelings. They are likely experiencing some of the same emotions you are, including anxiety and guilt. Anger and other negative emotions are also likely and normal. You and your family members can expect to feel hurt at times. Try to remember that these negative emotions are reactions to the situation and not to you yourself.

Trying to have a social life when you suffer from a *dysautonomia* can be a real challenge. People typically don’t like to hear about others aches and pains, or how poor health prohibits participating in social events, such as going to church, parties, movies, sporting events, or school functions.

Attitude is Everything

It is easy to take a defeatist attitude and give up. It is natural to have negative thoughts when your world seems to be crashing in around you. People with chronic medical conditions are susceptible to experience

increased emotional distress, fear, depression, anger, frustration, anxiety, or other negative emotions.

Even if you lack the physical capacity you had before becoming ill, you still have mental capacity. Consider Christopher Reeve. His paralysis didn't force him to give up. Instead he took his condition and gave the general public a look at the limitations that paralysis gives and turned it into an opportunity to help others who suffer from spinal cord injuries.

Lance Armstrong illustrates the power of determination and persistence. He was diagnosed with an advanced form of cancer that had already spread through his lungs, abdomen, and brain. He underwent extensive chemotherapy and several surgeries. Against all odds, he returned to the world of cycling and has won the Tour de France—repeatedly!

Some physical abnormalities in patients with a *dysautonomia* can themselves trigger mood swings. For instance, in several forms of *dysautonomia*, the blood pressure is extremely low when the patient stands up. This can evoke confusion, anxiety, or fear, due to decreased delivery of blood to the brain. In fact, mood swings can be a first indication of low blood flow to the brain. This may be a sign for you to increase your fluid intake. Remember it's wise to discuss changes in your mood, blood pressure, and other symptoms with your doctor.

Talking to others with the same condition can help. Even though we may not all have the same symptoms, we all have one thing in common—*dysautonomia* has changed our lives! There is nothing wrong with discussing your anger, frustration, concerns, and fears. A health psychologist may help you learn coping strategies. Some psychologists impress the importance of a “family session,” where all members of the family can relate the effects that the illness has had on them. Keep in mind that the entire family is going to be impacted by your illness. Support groups can also be very helpful. Among other benefits, joining a support group helps you feel less alone.

Take time to **recognize your abilities** and what you *can* do. For example, you may need help with grocery shopping but not with putting the groceries away. It may take time to discover what you can still do despite your limitations. Make small goals. Your goal today might be to walk from the bedroom to the kitchen. Next month it might be to clean the kitchen.

Keeping a positive attitude will help you move on with your life. You must meet your challenges with determination. Blaming or attacking your physician, family, friends, or even God isn't going to improve your health. Having a positive attitude may! A positive attitude can result in faster recovery from surgery and burns, give patients more resistance to arthritis and cancer, and help improve immune function. Remember that those around you will also be affected by your

illness. Your positive attitude will make things easier on your family, friends, neighbors, and yourself.

