Chapter 1

Dipping into Chronic Fatigue Syndrome: Symptoms, Causes, and Treatments

In This Chapter

- Finding out what CFS really is
- Understanding how CFS is diagnosed
- Discovering a treatment plan that works for you
- Helping a loved one who has CFS

Yes, that feeling of tiredness, that low energy, those nonspecific aches and pains — they're all real, and they may be signs of chronic fatigue syndrome (CFS), a condition that affects between 900,000 and 2 million Americans. Worse, approximately 80 percent have never received a diagnosis for their multiple unexplained symptoms.

If you suspect you have CFS, or if you have a loved one who shows signs of CFS, this book can help. In this chapter, I go over the main issues regarding telltale signs and defining symptoms of CFS, the whys and wherefores of the illness, and ways to treat it. I also refer you to the chapters where you can find more information on specific topics.

Taking Your Fatigue Seriously

Wouldn't it be great if you could just pull the covers over your head and not think about your constant fatigue? Being able to just ignore that low energy, the flu-like symptoms that just won't go away, would be wonderful. But unfortunately, pulling the covers over your head is just going to make you hot. If you've been suffering from fatigue in combination with some other symptoms for six months or longer, you may have CFS. In this section, I give you a basic picture of CFS.

What is CFS, anyway?

First and foremost, in order to be classified as having CFS, you need to have fatigue for *at least six months.* This fatigue can't be explained or has been a lifelong condition, and most importantly, plenty of rest doesn't take it away. According to the Centers for Disease Control and Prevention (CDC), you have to have at least four of the following symptoms in addition to the long-term fatigue to be diagnosed with CFS:

- Headache of a different type or length than the headaches you've gotten in the past — a headache like you've never had before
- Aching muscles
- Painful joints
- An increase in symptoms *before* exercise; exercise makes them worse.
- Sore throat that comes and goes
- Swollen lymph nodes in neck, , and underarms
- Short-term memory and concentration problems
- Unrefreshing sleep

In Chapter 2, I go over all these symptoms in depth, including several that aren't listed in the CDC's official definition for the illness but have been reported by people with CFS; these symptoms include chemical or food sensitivity, dizziness, depression, allergies, and irritable bowel syndrome (IBS).

How long does CFS last?

Asking how long CFS will stick around can be a tricky question. Just as CFS can come on quickly (as suddenly as a summertime flu) or slowly, with worsening symptoms over time, the duration of CFS is just as mysterious. Studies show that people who suddenly get CFS tend to have a faster and better outcome, but nothing is written in stone. The best way to improve your chances for recovery is to take care of yourself as outlined in Part III of this book.

Conjecturing about the Possible Causes of CFS

Researchers have been discovering more and more about CFS — what possibly causes it, why certain people and not others get it, and how it takes root — but they don't have any definitive answers. Basically, a variety of causes are being investigated, any one of which may someday be shown to be the illness's raison d'être. These possible causes of CFS include the following:

- **Your family history:** If another family member had CFS (or some of the symptoms of CFS), you may be more vulnerable to getting it; however, the jury's still out as to whether there's a genetic link. Some people with CFS in their family history live their whole lives without getting CFS.
- **Stress, stress, and more stress:** This possible cause can mean day-to-day mental or emotional stress or stressors such as illness or injury. You may have a genetic connection between your symptoms and the way your hormones react to stress. Basically, this hormonal reaction comes down to *allostatic load* (or AL for those in the know). AL measures the wear and tear your body goes through when stress rears its anxious head. Some early studies have reported that people with CFS may have a problem with the physical mechanism that generates a proper stress response, rendering them unable to react effectively to stressors (mental or physical).
- **Body chemistry:** Humans have an amazing messenger system — one that beats FedEx hands down. Your body produces chemicals in response to messages sent to and from the brain — chemicals that don't miss a beat when it comes to getting a good night's sleep or hailing a cab or deciding whether to get that dress in the store window. But as good as your chemical messenger service is, it can get out of whack — whether stress, illness, or emotion is the cause. Think of this chemical imbalance as a blizzard that stops the mail from coming in, one that may or may not bring CFS with it.
- **Viral infections:** You have a powerful immune system in your body, with antibodies and natural killer (NK) cells just salivating for some foreign virus to dare enter your cells. But unfortunately, your immune system isn't always perfect. It can fail to attack with the full force of its fury, not recognize the virus as an enemy, or may even overreact. This whacked-out immune system has also been linked to CFS.
- **Sleep problems:** Yes, it's true: Whether your sleep issues are due to stress, an overtaxed and overworked immune system with no downtime to rest, or just the lack of quality sleep in general, problems with sleep have been linked to CFS.
- **The HPA axis:** Doctors call the hypothalamus in your brain, along with your pituitary and adrenal glands, the *hypothalamus-pituitary-adrenal (HPA) axis.* The hypothalamus sends messages to the pituitary gland via hormonal (chemical) messengers. The pituitary gland, in turn, triggers the production of hormones in your ovaries or testes, adrenals, and thyroid glands. Some people with CFS appear to have abnormally low levels of the hormone cortisol in the blood, which means that a malfunction in the HPA axis may be a possible cause.

- **Inflammation:** Think of an inflammation as the way your body fends off viruses and bacteria — the first line of defense in the immune system. However, chronic inflammation can break down the immune system, which may result in CFS.
- **Autonomic nervous system dysregulation:** Your autonomic nervous system is responsible for all your critical body functions, from breathing and regulating your heartbeat to keeping your temperature on an even keel. Some people who develop CFS have an autonomic nervous system problem called *orthostatic instability (OI),* which means that staying in an upright position for more than a few minutes results in a feeling of dizziness; this feeling can occur when sitting or standing up. Because OI can be caused by dysfunction in the autonomic nervous system, your autonomic nervous system could somehow be involved in your CFS. However, some physicians believe that OI stands alone, a condition in and of itself; still others consider OI a symptom of CFS, not a cause.
- **Physical trauma:** Ouch! The aches and pains of a fall or an accident can hurt your bones, muscles, and even your brain. Not only can physical pain lead to all sorts of not-so-fun things — such as insomnia, depression, brain dysfunction, or even changes on a very basic cellular level in your body — but it has also been explored as a cause, trigger, or perpetuating factor in some cases of CFS.
- **Ongoing infection:** Sometimes the flu you caught at the office doesn't go away in the requisite two weeks. Sometimes the infection lingers . . . and lingers. And instead of feeling better, you feel steadily worse. Infection has long been suspected as a cause or trigger of CFS, but researchers haven't identified a specific virus or bacteria as of yet. It could be that by the time a person goes to the doctor after many weeks or months of symptoms, the bug is gone, leaving various forms of damage in its wake.
- **Environmental toxins and allergies:** Pollen, dander, mercury, and lead — these damaging substances may be involved in the onset of CFS in the same way infections are.

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Looking at the onset of CFS

Randall always considered himself one of those regular guys. He worked his 40 hours at a cellphone chain and stopped at a local bar for a glass of beer before heading home. He had a girlfriend of one year, Cynthia, and they were talking about getting married and having kids. He had good friends, and they never missed a football game or a poker night.

Things started to change gradually. It wasn't like someone waved a magic wand and made him sick. Instead, Randall came down with a bad flu. Cynthia stayed at his apartment and even took off from her receptionist job to take care of him. He got better and thought he'd licked the flu and could go back to work.

But Randall got better only to a point: He didn't have a fever, he was no longer congested and didn't have the chills, but his energy was zilch. Whereas putting in 40 hours on the sales floor was nothing for this 24-year-old before he got sick, it was now a huge effort. He ended up punching out earlier because he didn't feel well. He stopped going to the bar for a drink. He didn't feel like talking to anyone. His throat was scratchy, his body ached all over with the slightest exertion, and he woke every morning feeling as dragged out as he had the night before.

Randall cut back on his social life to hang onto his job and even drew away from Cynthia. He made excuses every weekend until Cynthia came over and confronted him one Saturday afternoon. She found Randall lying on the couch — mail, takeout boxes, dirty plates, and newspapers piled on the counters. The blinds were closed and the television was muted (noise and light just too much for him to handle). The house smelled musty, and the answering machine light blinked, indicating lots of unreturned calls.

It may have looked like Randall was depressed, pure and simple. The lethargy, the isolation, the way he'd let things around him go — all these signs pointed to depression. But there was more to it than that, and it was called life-draining, exhausting, feet-dragging, barely-able-to-tie-his-shoes fatigue, not to mention the other symptoms that pointed to something different.

In addition, whenever Randall tried to get out of his slump, he was even more exhausted for several days afterwards. The day Cynthia came over, he tried to take a shower and get dressed to go out. Before the movie they went to see ended, he was so tired that they had to leave. He didn't get out of bed for days afterwards.

This pattern continued for months, and then gradually Randall began to feel better. But three months later, the fatigue, the aching muscles and joints, the sleep problems, and the sore throat all came back threefold.

Randall went to see his doctor. His job was on the line, and he was worried sick: "When will I feel better? Will it come back?" His family doctor referred him to an internist who had treated other patients with the same symptoms. The doctor put him on a low dose of one of the newer antidepressants that also helps with immune function and pain. He also gave him something to help him sleep through the night. In addition, he recommended making some adjustments to his work schedule and taught him some energy-conservation techniques.

After a lengthy diagnosis procedure in which the doctor excluded other conditions, the doctor gave Randall a name for what ailed him: chronic fatigue syndrome. This diagnosis helped Randall find information about his condition and connected him with others who understood what he was going through. It also gave Cynthia a framework to provide help and improve their communication about what was going on with Randall and their relationship.

Today, Randall is doing better, but he keeps a lighter routine than before. He paces his activities and takes rest periods throughout his day. He sees a therapist every week to help him (and sometimes Cynthia, too) adjust to the changes in his life brought on by illness. He uses coping strategies when faced with stress, and he isn't afraid to reach out and ask for help from people in his CFS support group. And, oh yes, he and Cynthia said "I do."

To find out more about the possible causes of CFS, check out Chapter 3, which gives you all the dirt on the whys of CFS.

Seeing the Right Kind of Doctor

Research from the Centers for Disease Control and Prevention (CDC) shows that the longer a person has CFS without being diagnosed or treated, the less likely he or she is to improve — and the more complicated the symptoms are. So getting an early diagnosis and treatment for symptoms is essential! And that starts with the doctor himself.

Try contacting your local hospital or a local support group for information on doctors who are knowledgeable about CFS. And remember to ask your friends or people in the local CFS support group. You'd be surprised to know that many of them understand what you're going through and may know of an excellent doctor. Of course, before you go to any doctor, check with your health insurance company to make sure the physician is part of the network.

Although you may forget the idea when you see the white coat come into the examination room, the doctor is there for *you.* If you feel your doctor isn't taking you seriously, or if he comes out and says that CFS is all in your head, run (don't walk) to the exit. Remember you're dealing with your health and your life — and you deserve the best. To find out more about finding a good doctor, see Chapter 5.

When you get to the doctor, remember that he may not be fully versed in CFS, but that doesn't mean he's a bad doctor! Work *with* him. Do the research. Bring your questions. CFS is usually the illness of last resort, when everything else has been ruled out, so be patient and make sure you're getting treatment for your symptoms. You can flip to Chapter 6 for more on making sense of your symptoms and Chapter 7 for info on possible treatment options.

Ruling Out the Other Suspects

CFS is more a case of what it *isn't* than what it is. You need to work with your doctor to rule out any other possibilities before coming to a CFS diagnosis. A few conditions that generate symptoms similar to CFS include the following:

- **The plain, old flu:** The flu, an infection with the influenza virus, has many CFS-like symptoms, such as fever, sore throat, and swollen glands; however, unlike CFS, the flu generally doesn't last six months or more.
- **Fibromyalgia:** This condition is also one of the hard-to-diagnose illnesses, with many of the same symptoms as CFS. The main difference between the two is that fibromyalgia's primary symptom *has* to be aching muscles and joints, and the first symptom of CFS *must* be fatigue.

- **Lyme disease:** CFS and Lyme disease have a lot of overlapping symptoms, and exploring whether an infection of Lyme may be the cause is worth the effort.
- **Hormonal disorders:** From your thyroid to your adrenals, hormonal dysfunction can make you feel tired, foggy, bloated, and just not yourself.
- **Sleeping disorders:** Everything from sleep apnea to snoring to insomnia to a bad mattress can interfere with a good night's sleep.
- **Depression and other mental disorders:** A clinical depression that makes you feel hopeless and helpless, or generalized anxiety that threatens to overwhelm you can mimic CFS. A thorough evaluation, specialized questionnaires, and some medical tests can help distinguish between common mood disorders and CFS.
- **Eating disorders:** If you don't eat, have poor nutrition, or throw up after you eat, you're going to be tired and have numerous unexplained symptoms. Period.
- **Autoimmune disease:** The symptoms of certain autoimmune diseases, such as lupus, can mimic those of CFS.
- **Obesity:** Lugging around even ten extra pounds can make you sluggish and tired. Being significantly overweight creates significant stress on many body parts, generating multiple and varied symptoms.
- **Substance abuse:** Alcohol and other drugs can cause all sorts of side effects — including fatigue.

These conditions and more can all mimic CFS, and you may not have CFS at all. To check out these "fakers," go to Chapter 2. To read about how the doctor rules out other conditions in order to properly diagnose CFS, head to Chapter 6.

Drafting an Effective Treatment Plan

Because CFS is such a complicated illness, with symptoms that can vary from day to day or week to week, having good treatment and a good treatment team are vital to your well-being. See Chapter 7 for a more complete look at different treatments, but in the meantime, here are some treatment success stories in brief:

- **Medications:** From painkillers to antidepressants, doctors can prescribe or recommend a host of medications that can help reduce symptoms and improve your ability to do everyday things.

- **Individual psychiatric or psychological therapy:** One-on-one mental health therapy can help you sort out your frustrations and your anger about your condition — not to mention how it has changed your life and relationships. Therapy is a vital part of your treatment plan to help with depression or anxiety if these symptoms are present. (You can find more info on therapy in Chapter 8.)
- **Family and relationship therapy:** No human is an island, which means that everyone has family or relationships that are important to him or her. In order for you to get the best care — and for those you love to have some respite — therapy for them (or together as a family) is an excellent idea.
- **Complementary alternative care:** Although the jury is still out on herbs and supplements, alternative treatments such as massage, yoga, and meditation can help relieve the stress that you may have. (To get the skinny on alternative health care, you can make a beeline for Chapter 9.)
- **Restructuring your life and sleep:** Because doctors can't tell when a person with CFS will get better, figuring out how to adapt and cope with the physical, mental, and emotional changes brought on by the illness is vital if you have CFS. Coping mechanisms need to be in place so life doesn't stop.

  Many people with CFS have sleep problems, so addressing your sleep is very important, because it may require medications or something as simple as not sleeping for long periods in the daytime. Either way, restful sleep is a big priority. (For more sleep advice, see Chapter 11.)
- **Feeding your nutritional needs:** Eating healthy can keep your blood sugar levels balanced — which means more energy, less fatigue, and a better mood for you. Chapter 11 gives you the nitty-gritty details of a well-balanced diet.
- **Exercising nice and easy:** Exercise is important to prevent becoming deconditioned, but it must be designed for each individual. The important point is to start very slowly, increase very slowly, and always rest during exercise sessions. Pace yourself to find what works best for you without overexerting. You need to find that happy medium: not too little and not too much. (Chapter 10 has what you need to know about exercise and CFS.)
- **Getting rid of stress at work or at school:** You need to take breaks and regulate your schedule. Talking to the guidance counselor or to human resources to see whether you can have a more flexible routine may help. (But make sure your company is supportive before talking.) It may be necessary to involve a doctor, occupational therapist, and the Americans with Disabilities Act (ADA) in this type of workplace disability issue.

Keeping Love Alive in the Midst of CFS

What's love got to do with it? Plenty! Whether you or someone you love has CFS, the illness affects both of you. You need to be conscious of not only how you're feeling and what you're going through but also the needs of your spouse, partner, or other loved one.

Whether you're the caregiver or the person with CFS, there's a give-and-take that must be maintained. The person with CFS has to figure out how to set boundaries, and the caregiver needs to take care of himself or herself, too. In this section, I highlight some of the CFS relationship topics you can find in Chapters 13 and 14.

Appreciating the care others give

If you have CFS, make sure you tell your loved one how much you appreciate him or her. In addition, you may also want to consider doing the following to help out your caregiver:

- Work out a schedule with a few people to help out with different needs: the kids, the housecleaning, dinners, or even grocery shopping. This way, no one gets the brunt of taking care of you and everyone's happy. It's a win-win situation.
- Make sure you thank your caregiver — and not just once! A person can't hear thanks enough!
- Make sure your caregiver takes some time out. If your caregiver can't take care of himself or herself, your loved one won't be able to care for you.

See Chapter 13 for more handy tips on keeping relationships alive when you have CFS.

Supporting a loved one who has CFS

If you happen to be a caregiver, rather than the person with CFS, taking care of yourself is just as important as caring for your loved one. If you don't, you won't have any energy left over to help your loved one and keep up with other responsibilities you may have.

TIP

Here are some quick tips for taking care of yourself:

- Acknowledge your feelings and discuss them calmly and honestly.
- Don't burden yourself with the responsibility of making decisions alone. Have the person with CFS and other family members help you find solutions to problems.
- Take a break. Enjoy your hobbies, take a bubble bath, go to the store, or otherwise step back every once in a while. Your friends and family can give the person with CFS a change of company, watch the kids, or take care of chores for you as you recharge.
- Ask for formal help if you need it. Talk to a financial planner if you're worried about finances, or discuss emotional concerns with a therapist or support group.

By taking care of yourself, you're better prepared to care for your loved one. For an expanded discussion on caring for someone with CFS and attending to your own needs, Chapter 14 is where you want to go.

Guiding a Child through the Trauma of CFS

Children often have a hard time describing exactly how they feel. Not possessed with a huge vocabulary, "It hurts," "I'm tired," "I'm sleepy," and "I feel yucky" may be all they can muster to tell you how they feel. As you and your pediatrician try to figure out what's wrong, your child may have to visit many specialists, be subjected to numerous tests, and be put on a special routine of diet, exercise, and rest. Adding the suspicions of other family members, teachers, and friends that he's only faking can make the process of diagnosis, treatment, and lifestyle adjustments difficult for your child.

How can you help him adjust to the reality of living with a chronic illness? You can't find an easy answer, but the best approach is to be honest with your child. Educate him about CFS in terms he can understand, and involve him in the decisions surrounding his treatment and long-term care. Giving him a sense of control over his treatment can go a long way in giving him a sense of control over his life with CFS.

And kids who have CFS aren't the only ones who can be a concern. If your children see that you're incapacitated or sick, they may get frightened. They need to understand what's going on.

In the following sections, I give you a brief overview about how to help your child fight the battle with CFS, whether he's dealing with it himself or has to adjust to a parent having the illness. For more detailed advice, see Chapter 15.

Educating your child about CFS

The first step in educating your child about CFS is to educate yourself. You can accomplish this by talking to your child's doctor. You can also find numerous publications available free of charge on the Internet from reputable sites such as the Centers for Disease Control and Prevention (CDC), the National Institutes of Health (NIH), and other medical Web sites, such as WebMD. (For a list of these and other CFS resources, turn to the appendix in the back of this book.)

After you feel like you're getting a good grasp on what CFS is and how it will affect your child's life, you need to take the next step of imparting that information to your child. You have many options available to you to help out with this process. Many CFS foundations and organizations offer booklets and brochures for all age groups. The CFIDS Association of America has a useful Q&A section on its Web site with ready answers to many of the questions your child may have about CFS. (You can visit the site at `www.cfids.org/youth/articles.asp`.) But the most important thing to tell your child as you help him understand CFS is that you can do things as a family to help ease his symptoms — and that you love him no matter what.

Attending to your child when you have CFS

The most important element in caring for your child when you have CFS is to keep the lines of communication open. If your child feels secure enough and loved enough to talk to you, you can find out exactly how she feels, how she is coping, and how you can help.

Also, don't forget to allow your spouse or a close friend to help out with some of the daily needs your child may have, such as getting her meals, taking her to school, or doing her laundry. You can focus on helping your child in ways that aren't taxing to you and allow you to spend some quality time with her, such as by helping out with homework, combing her hair, or reading out loud.

Anticipating Future Tests, Treatments, and Possible Cures

The future of CFS has exciting possibilities. From genetic research to studies on the immune system, researchers are finding out more and more about the links to CFS. In the meantime, you can do the following to stay up-to-date with CFS news:

- **Stay informed with a support group.** Other people with CFS may have heard something you haven't — and vice versa.
- **Participate in a clinical trial.** If you meet the criteria of the aspect of CFS that's being studied, you can experience new findings firsthand.
- **Use the Internet.** You aren't alone. Over 900,000 Americans are suffering from CFS, not to mention thousands of others worldwide, and many of them are using the Web to seek out support, answers to questions, and physician referrals (and you can, too!).

See Chapter 16 for more information about exploring future treatments, participating in clinical trials, and finding out the latest information.