CFIDS Association of America
working to make CFS widely understood, diagnosable, curable and preventable

Hope: From a YPWC

By Dianna M. Banks

Chronic fatigue and immune dysfunction syndrome (CFIDS) first emerged slowly a few years ago gaining recognition as the "yuppie flu," a luxury illness which struck only well-to-do young adults. As time passed CFIDS gained validation as an illness elusive to diagnosis, yet tragically real. Afflicted adults came forward with their harrowing personal experiences and in turn did receive some reluctant medical acceptance. With the emergence of CFIDS as a real disease also came the heated controversy and fierce medical debate which forgot a minority of those also stricken: the children and adolescents with CFIDS.

Though their exact numbers are uncertain, many children and adolescents suffer silently with an illness few know about and even fewer understand. These children share the same agonizing symptoms as their adult counterparts, yet they are different. Some are too young to remember the days when pain only came from a scraped knee or sadness from harsh words. Others, such as adolescents, question where their childhood went, and wonder why they are being forced to live in a daze of physical pain and mental anguish.

I'm one of those who remember vaguely what it was like to play, to have friends, to be healthy. Though I was often sick as a child, I do remember that inexhaustible source of energy that drives most children to be physically active. I played, had friends, attended school, and had a great relationship with my parents. We participated in vigorous activities, such as skiing and karate.

I describe these things not out of memory, but from family photos and word-of-mouth. Honestly, I can't remember a time when my father, my mother, and I did all those things. Before I was even ten, I found out my mother was sick with CFIDS. I didn't accept this drastic change in my life, and for a short time, I even rejected my mother. I didn't understand why my mom was so different from other moms, why my mom was sick. I resented this because I didn't understand it. Only later would I truly comprehend my mother's pain.

When I first became ill with the same illness that had struck my mother, I was told I was faking, that I just didn't like school. The situation was just the opposite. I had always loved school and, being a smart child, had always done well. Now something was taking that away from me. I was dragged to every specialist there was and the diagnosis was always the same: there wasn't one.

My symptoms began in 1987, when I was only eight years old. I had nausea, joint/muscle pain, headaches, abdominal pain, and of course, fatigue. Three years later I was diagnosed with CFIDS by noted CFIDS specialist Dr. David Bell. I was relieved, as were my parents, that my illness was real. Then the reality of my new life set in.

I missed all of sixth and seventh grade and most of eighth grade. Since I was mostly bedridden, I needed my mother's help to get to and from the bathroom.

I don't remember much of the pain of those three years, but I will tell what I can. I wish to tell other adolescents involved in the same struggle that they can succeed as I have. When I speak of succeeding, I will try to help you find ways to cope with CFIDS and to take pride in the strong person you will become as a result of your survival.

Part One: DEVELOPING A HEALTHY RELATIONSHIP WITH YOUR MIND

Before you can even begin to cope, you must find a few things out for yourself. By now you already know that your case of CFIDS is probably the most devastating event that has ever happened to you. Realize that, don't minimize the pain in that knowledge.

Living and surviving with CFIDS is a lot like the stages you would experience after the death of a loved one. You deny it, acknowledge it, resent it, and finally accept it as an obstacle, or stumbling block, not as something that has "sealed your fate." No matter how emotionally healthy you are, you must feel your way through each emotion to find peace. As cliché as that might sound, it does own a great deal of truth.

This section discusses the stages of dealing with CFIDS I personally experienced. They may not be in the same order as you experience them or maybe you'll find that they don't hold true for you at all. I do hope that they help you on your own path of coping, or at the very least, bring you some comfort.

DENIAL

In nearly every tragedy, denial is usually the first emotion one feels. The same principle applies to people when they are first stricken with CFIDS: This isn't real. I used to think, "I'm not really sick, maybe I am truly insane." Denial can be spurred on by ignorant doctors who, without a concrete diagnosis, claim you are well. You just suffer from hypochondria, right?

Unwittingly, family might also contribute to this surge of denial you feel. My father used to liken this situation to a snowball rolling down a hill; it picks up more speed and it becomes bigger until it's no longer a tiny snowball. The same applies to family members who want you to be well so badly that they can disbelieve the evidence before their very eyes. If your family pushes you to be physically active in a way that you are incapable of, try to let them work through their own feelings. Don't give the "snowball" more power to grow bigger. Your family must learn to accept your illness, just as you must.

I found my teachers unwilling to believe in the validity of my illness. They saw this "straight-A student" who couldn't participate in their classes anymore. Some of them even went so far as to hint that I was a school phobic. This situation, should you encounter it, might seem very bleak, but it is not. You must present yourself as someone who wants to learn and is willing to give his/her best effort to school work. If this fails, be persistent. Even the most "thick-headed" teachers will eventually meet you half-way with some alternative learning accommodations.

Next to acceptance, getting through the stage of denial is the hardest step of all. Establishing a good relationship with yourself is most important. Give yourself the time you need to work through this. I personally did three things during my denial stage that I regret, but you must learn for yourself. I call them "fighting," "pushing," and "refusal." Although these aren't professional terms, I think every young person with CFIDS (YPWC) does do one or more of these.

"Fighting," quite simply, is fighting yourself. I often had a two-sided war going inside my head over my diagnosis. One part of me believed in the validity of my illness and the other half didn't. I could convince myself I wasn't sick and that I was just "mentally" ill. "Fighting" is probably the most disturbing part of denial I went through because there was no escape, no refuge even inside myself when I was constantly at war in my mind.

"Pushing" is putting your body through rigorous activity to "test" your health. After diagnosis I gave myself unreasonable physical goals. I exercised more and gave my body less rest. This sort of behavior was quite normal (in my eyes): Who wouldn't want to prove themselves wrong in this case? Who wants to be ill? Not many people do.

I found "refusal" to be quite similar to "pushing" in that in both cases I went about my daily routines in life. I refused to back off and give my body the rest it needed. I went to bed at the same time, even though I lay there for hours. I ran around like every other person my age no matter what the consequences to my newly fragile health.

ACKNOWLEDGMENT

After you have overcome denial, which is a lengthy and very painful process, comes acknowledgment. You know you are sick and give your illness validation in your mind.

Acknowledgment is a mixed blessing to a YPWC. It is heartbreaking for you and those around you to accept that this nightmare is yours. With the pain of realization comes some inner peace. Since you are not fighting yourself, your mind and your body can begin to work with each other in healing.

Discovering that I really had CFIDS (I mean, really knowing it) was at once both freeing and terrifying. I was free from pushing against my own body and making it sicker, yet I now realized I had to make many life changes. My body was not the same, and therefore I was not the same person.

There are two ways YPWCs can experience enlightenment after denial, which may have taken months or years. First, is by having their body give out from fighting or pushing; secondly, finally hearing themselves.

I experienced both. I went through exhausting my body with normal activity which it was not capable of and I listened to my heart. I knew that no matter what any one else said, I had enough faith in myself to know that I was not making this up. I no longer cursed my body for faltering at times and I paid attention to my pain, adjusting my activity so that I was in sync with my body.

Though I reveled in this new relationship between mind and body, I still had a lot to deal with. Even if my body recovered from this illness I knew that my life would never be the same, but there wasn't enough time for me to think of this. I was in pain every day; every waking moment something hurt me. I needed help to get to the bathroom and taking a bath was an accomplishment. I relied on my mother for my survival. She brought me food, she helped me to the bathroom, but most importantly, she held me when I was in pain.

I was very fortunate. During realization, YPWCs need someone to believe in them, to help them not just physically, but mentally. It is especially important as a parent to recognize this need in your child and to respond.

I found that the power of touch made a world of difference in my physical and mental anguish. For mental survival, I can not reiterate enough how important it is to be touched or even better, held by a loved one. For me, my mother didn't just provide contact comfort, her touch made my pain less intense, more bearable.

As a YPWC, don't deny yourself this comfort to prove how strong you can be. People need people, there is no exception to that rule. Strength is found in realizing our basic human interdependence. So don't deny yourself comfort and relief of your pain for valor. A truly strong person recognizes when they are the most fragile.

ANGER AND RESENTMENT

After acknowledgment comes probably the most emotionally wearing part of coping with CFIDS. Following the acceptance of my illness, I was furious. I had many thoughts, two of which were recurring for me.

Recollection: I remembered all the times I'd been sick as a child with a cold or had fallen and hurt myself. I had healed with little time and suffering. Why were things different now? I kept trying to imagine how long I would be sick with CFIDS and whether I would be able to heal myself so easily. This time I knew things were different: there wasn't any medication to cure me and no one knew how long I would be sick. I longed for someone to make this sickness and pain go away, but there was no relief, mentally or physically, in sight. I spent my days angry and resorted to tears at night.

Wonder: I had another recurring thought when I was very sick, that would give me no peace: Where was I when this happened? What was I doing? I couldn't stop thinking about what I might have been doing the very instant when this illness took over my life and body.

I was often angry at myself for getting CFIDS. I wondered if I'd forgotten to wash my hands just once or been in the wrong place, either of which could have made me sick. I knew this was an irrational line of thinking, but it is normal. Whenever we encounter any major life change we ask "why?"

I still have many questions about CFIDS, but along the way I have found some answers within myself to the questions I'd asked.

When you find yourself wondering how long you might be sick, you will have to accept the truth: you can't be sure. This is extremely difficult when we live in a world with such technology that can predict the weather, days ahead, down to the exact temperature. With CFIDS a lot is unknown, and being a survivor of this illness is learning to take things day by day.

Another answer I discovered regarding the question, "Where was I when this happened...?" is: you most likely will never know. Despite this, you must realize that there was nothing you could have done to prevent this illness from happening to you.

CFIDS is not a punishment for uncleanliness, bad deeds, or bad timing. You are the "victim, with regard to the responsibility for your illness. I use the word "victim" only to convey a point, because I do not see myself as a victim and neither should you. A victim is helpless and I am not and neither are you. YPWCs can work within the bounds of their illness and still achieve their hopes and dreams. Accomplishment makes YPWCs survivors, or people who triumph over adversity (CFIDS) to live their lives to the fullest.

WHY ME?

I left this question its own section because I'm convinced it is the biggest inquiry people suffering from CFIDS have. This question tortured me for years. I would lie in my bed and the words "why me?" constantly reverberated through my mind. What had I done to deserve such an undignified and painful fate? I had several theories on why I had become sick.

"I'm just not worthy of health": I continually told myself that I had done something in my life to have been dealt such a cruel hand. For years, I regret to say, I actually had myself convinced that I had committed some terribly wrong deed and I was being punished for it. I got to a point where I sometimes refused medication for my pain because I thought if I just suffered, my ill deed would be purged. This sort of response is very negative and can only bring pain. If I can offer any comfort in this area, let me reassure you that CFIDS is not a punishment for anything you did. This is an unfair deal for anyone regardless of their past. No one is to blame.

"Why don't the 'bad' people in the world have CFIDS instead of me?: If YPWCs must accept that CFIDS is not a punishment doled out to them, it wouldn't make sense to have this illness given as a punishment to another "more deserving" person. Sadly enough, I have noticed that most of the people I have encountered who have CFIDS are some of the most intelligent and kind people one could ever hope to meet. This is a gift in a way when you consider how great it is to receive support from such people.

"Is this an omen or divine punishment?: I believe this to be a very critical question that nearly all people with CFIDS ask themselves, regardless of how ridiculous it may sound to others. I found myself asking this quite often. Had I done something wrong (sinned) or was this an omen that I wasn't worthy of health? I do not believe that any supernatural power(s) would purposely make you suffer on a daily basis as you do. Some people I've met consider their illness a test of their personal strength and kindness to others. I don't think that's true.

ACCEPTANCE

When faced with a chronic illness, or any major life change, acceptance of this change is a very important step toward inner peace. With acceptance comes the relief that you will no longer fight your body, but recognition that you do have certain limitations. With this final mental step you come to understand that you don't need to conform your life to the boundaries that CFIDS gives you. You will be able to appreciate the strength of your body when you are having a good day.

When you have gone through all of the steps I mentioned previously, your mind will naturally end up at the stage called acceptance. Don't force yourself prematurely into this step. Let your mind work through things in its own way and on its own timetable. Each person is different, therefore the period of time needed to reach this step is different. It can take months or even years.

In my case, it took me at least five years to accept CFIDS as a part of my life. Over the last few years, reaching this stage has brought more peace to my mind and body. You can expect to have lapses into any previous stage. Try to just accept this and realize you have a right to feel that way. Take a few minutes to say to yourself, "Hey, this really stinks. I deserve better, I hate this damn illness." Just let your mind work through each emotion you encounter.

A gift that comes with reaching acceptance is being able to focus more on the world and people around you. When you first become ill, your body and mind are forced to avert all attention inward for healing.

When you reach acceptance, you are able to clearly look around your world and realize things you hadn't noticed before. First, the world has continued around you, even though it feels like it had stopped with your illness. Knowing this, put yourself into the real world again. Continue with school, your hobby, etc.

Most importantly, you can now see how much your family and friends have been through. Hopefully they've been there for you, supporting you during your ill health. Realize that people care about you and are willing to help. Take a minute to thank them for their love. Then take the hand that is offered to help you - doing so is the greatest part of acceptance, which is realizing that you don't have to face CFIDS alone.

In conclusion, there isn't any specific time limit on how long it takes to get through each of these stages of emotional conflict, nor must you experience all of them. It is important to remember the physical part of your being as you work out all of these tremendous thoughts in your mind.

After I experienced each stage and gave each one my full attention, I found that I could better work with my body to cope with this illness. I discovered that my mind, body, and spirit were all connected and that I had to take care of each to reach complete health.

Despite the difficulty of working through each stage of CFIDS acceptance, it is worth the results. The mind has so much power over the body, more than doctors, with their modern technology, even know about. Working through each of these steps will eventually give you inner peace and then you can begin to work on healing your physical self.

Part Two: DEVELOPING A HEALTHY RELATIONSHIP WITH YOUR BODY: THE CFIDS DAILY LIFESTYLE

After I worked through the mental pain of dealing with CFIDS came the easier part for me: helping my body so that it could, in turn, help me reach my goal. My goal was simply to get better using whatever techniques and strategies I could utilize. Since there weren't any tips or suggestion for PWCs, I had to devise my own plan of battle against this illness.

What I learned from being bed-bound right from the start was that lying around in bed, with no stimulation or pleasure in my life, was hurting my body more than helping it. I found that I became more tired and even more depressed. I wanted to change this, but I had limited resources to draw on. My body was weak and I had little motivation.

ESTABLISHING A ROUTINE

Using the idea that staying in bed in my pajamas all day wasn't helping me, I came up with a schedule. This may sound like a lot of effort for someone who is very sick, but it's well worth the rewards.

To develop a way to cope with "The CFIDS Daily Lifestyle," as I call it, I began to try to wake up at the same time every day. This is extremely difficult to attempt, especially when you've been up until the early hours of the morning with pain, but it gave me some feeling of power in my life. For the first time I felt as if I was controlling my own actions, that CFIDS wasn't calling all the shots any more. This is very hard at first, but be patient with your body and give it time to adjust to just getting out of bed.

After getting up, my routine included washing my face and brushing my teeth. This may sound ridiculous to people without CFIDS, as well as to you, because nearly everyone takes these simple chores for granted. Once you've had CFIDS, they become major chores, requiring much effort. Next I brushed my hair, sometimes I even got dressed. "Getting dressed" for me, when I'm sick, is as simple as putting on sweats. It isn't so much the clothes you put on as it is the feeling of accomplishment and control this simple act gives you.

Add your own parts to your personal hygiene routine, but remember to choose somewhat simple goals and make sure that you always do them. Even on a down day, this may be enough to lift your spirits. Your mind needs something familiar, some continuity to maintain emotional health.

MODERATION AND EXERCISE

In going about the rest of your day, even if you can't get out of bed for a short amount of time, the key to anything with CFIDS is moderation. Doing things in moderation, or small amounts, may allow your body to be able to do things you didn't think were possible.

If you feel well enough, take a walk, leave your bed for a different area of the house, anything in small amounts. I'm not saying to begin walking miles every day, but do a little bit of the things you want to do while maintaining self- control. Self-control is vital when dealing with a CFIDS body. While you may feel temporarily good taking that long walk, you may use up all that precious energy that you could have used to accomplish something else you enjoy.

MAINTAINING MENTAL FUNCTION

What I've found is more important than physical health is maintaining mental alertness. While the power you have over your mind to focus may be limited on certain days, it is important to use it anyway. Play a mind-bender game, do a puzzle, or find a hobby that doesn't consume too much energy. My hobby when I was very sick was collecting dolls and teddy bears, so that even when I wasn't well enough to play with them, I could still look at them from my bed. Whether it's stamps, game cards, comics, etc., be sure to stick with something that brings you pleasure, which will help you retain mental alertness no matter how sick you are.

Part Three: SLEEP: COPING AND CHANGING

The most challenging obstacle I've overcome, without a doubt, has been learning to cope with the sleep problems which come with CFIDS. At my sickest, I was perpetually exhausted and lethargic, yet going to bed yielded little rest and caused me the most frustration. For everyone, sleeping is a vital reprieve from the physical and mental strain of the day. For the person with CFIDS, sleep becomes even more crucial to repair the daily aches and frustrations of dealing with the illness.

The YPWC has no lack of need for rest, but often going to bed just ends in tossing and turning and a feeling of exasperation in not being able to "handle" CFIDS. During the day you might, with great effort, be able to cope with the pain and mental fatigue of a chronic illness, but even the most seasoned veteran is exposed to the heightened awareness of the symptoms. A PWC's desperate night struggles are easily understood using common sense.

By the time the body is ready to sleep, its weariness is a signal to your brain that your threshold for any sort of strain has been exceeded for the day. Pair physical fatigue with nightly CFIDS aches and feelings of isolation from others who are sleeping, and nearly everyone can appreciate the YPWC's plight.

CHANGING YOUR SLEEP HABITS

The first step in gaining control of your sleep patterns, and thereby getting more control of your life, is to once again use a schedule! Make a chart of the time you go to bed. At my worst, I was going to bed anywhere between 5 am and noon. Mark down your "bedtime" and then find out what your "wake-up" time is. Mine was around 5 pm. After writing all this down, you will then notice a consistent pattern of how much sleep your body now needs.

Now comes the hard part: moving back those hours to begin a new sleep rhythm for your body. Let's assume you went to bed at 3 am. By implementing your new schedule, you'll go to bed at 2:30 am for a few days.

Don't be disheartened if you have trouble sleeping or all is not accomplished in one night. Be forgiving with your body, it needs time to adjust to this new schedule, as it changed with the initial invasion of CFIDS. Take a week for each whole hour you move back. If this is successful, your time of waking up should move back also.
Perseverance is the key to changing your sleep. The rewards are well worth the struggle.

COPING WITH YOUR SLEEP PROBLEMS

There are many problems that CFIDS throws at your body to disturb its sleep, but fortunately, there are just as many things you can do to cope with these intrusions upon your rest. These are just a few of the tips and techniques I've discovered (maybe others use them also) to maximize the amount and quality of sleep I've gotten through various stages of CFIDS over the years. These ideas can be used to help get you through the rough spots when changing your sleep schedule or to help you if you're too sick to work on your schedule right now.

If you've already changed your bedtime, congratulations! If not, have a specific bedtime anyway. For the sake of your body, try to maintain continuity when deciding what time to turn in. Even if your bedtime is 4 am, stick to that time and temporarily let your body adjust to this new routine.

A great way to induce sleep is to have a ritual in which you prepare for bed. If you have the energy, take a bath each night. The warm water will slow your body down and raise your temperature, which automatically signals your brain that it's time to get to sleep. Another ritual might include reading a few chapters in a book each night before bed. I wouldn't use TV because of its stimulation through sound and bright lights. It will just tell your brain to click right back on.

Another tip for insomnia related to CFIDS is to keep your bed off-limits during the day. This is not possible for those who are very ill and need strict bed-rest, but there is a reason behind this tip. If you spend all day in bed or simply lie in bed reading at night, there isn't any way for your brain to know when it's a good time for sleep. If you are limited to lying down, lie on the living room couch or sit in a comfortable chair during the day. By using this idea, I trained my mind to realize that when I'm lying down in my bed, my body wants to sleep.

No matter what your patterns of sleep are, be patient with your body. While it's easy to lie awake at night and dwell on CFIDS related problems, you must have the confidence in your body that it knows what it needs right now.

When it comes to tackling the CFIDS sleeping problems, you must strike a balance between the control you exert over your sleep and allowing your body the rest it needs to fight this illness. Learning to listen to your body's needs is the greatest accomplishment a person with CFIDS can have. When all else fails, the light of day will always show up soon.

Part Four: CFIDS AND THOSE AROUND YOU

When people are diagnosed with an illness, they tend to focus on themselves and how it affects them personally. This mechanism is not selfishness, it is simple human behavior which has adapted all of us for survival. When stricken ill, we must be short-sighted and focus on our goal of regaining our health. With a simple cold, this process takes several days or weeks before the goal is attained.

With a lingering illness, such as CFIDS, the person is forced to look into a future of several years. Learning to grapple with future prospects is good, but sometimes we need to look not forward, but around us. This is the time when YPWCs realize that they do not suffer alone.

CFIDS AND YOUR FAMILY

Of all of the people who will be touched by your illness, your family is hit the hardest. They have known you for many years and have come to love you for the person that you are, so they are directly affected by this illness. Your family includes your parents, your siblings, and others close to you. As the person stricken with CFIDS, your goal is to help them to understand and cope with your illness as you have. Each member of your family is different and each has different levels of intimacy with the others. Recognizing this basic fact will help you in your pursuit of a relationship with them.

As a YPWC, your relationship with your parents is most likely under a great deal of stress. This is completely normal, considering how all of your lives have changed so drastically. Since each of your parents is an individual, each will react differently to this change. Your best hope of reaching an understanding is to discover what feelings are eliciting their reactions.

When I was diagnosed, I was fortunate in the fact that both of my parents believed in the validity of my illness. I had other obstacles to overcome in dealing with them though because both reacted differently. My father took a very masculine approach in dealing with me being ill. He would insist on having me in bed at the same time every night, even if I wasn't tired. I remember lying awake for hours, unable to sleep and feeling very alone. Later, my father realized the error in this and took a more gentle approach to my illness. My mother was forced to care for me as if I were an infant and truly took on the role of a protective mother. Over the years of dealing with CFIDS and how it related to their child has helped them both refine their style of parenting to accommodate this major part of my life.

When trying to understand why parents react in a certain way, keep this thought in your mind: "I am their child." When you remember this, you will be able to comprehend how difficult it is to see someone you love very ill and will understand their feelings of helplessness and hopelessness.

When you are finding a parent is approaching a CFIDS-related matter in an unconstructive way, gently suggest the course of action that would make them most comfortable. Remember to always keep the lines of communication open. No matter what the problem, communication among the members of the family is the foundation of healthy relationships.

FRIENDS

One of the most challenging social problems for a YPWC concerns friends. The two main questions I often found myself wondering were: "Do I tell them I'm sick?" and "Should I still set up times to see them?"

The answer to the first question depends on several factors including the amount of intimacy involved in the friendship and how you want to handle this situation. I personally tried to hide the nature of my ailment from my friends for a while, because of my pride and fear of the lack of understanding I might receive. If you call someone a "friend," then you most likely have a pretty good idea of how that person might react to the news of your illness.

A lot of people will stick by you and support you, but in reality, others will not. While this is painful, keep two things in mind. First, the person that rejects your friendship may not be good with dealing with sick people. They feel at a loss for what to say or do and are frightened by their own confusion. Second, if a "friend" reacts to this news by breaking your friendship, take some comfort in the fact that they probably weren't worthy of your friendship. Dealing with CFIDS will prove time and time again who are your friends are, and who aren't.

If you tell your friend and your relationship continues (congratulations, you have a true friend), then you will most likely wonder if you should continue to make plans to see them. Sometimes you will plan a time to see a friend and not be able to go simply because you aren't feeling well. When this happens, don't be harsh on yourself or resent your body, it just needs rest for the next time you go out. Just explain to your friend what happened and he or she will most likely understand.

Never, ever let CFIDS make you isolated from the world and the people in it. You deserve to be loved and have fun, so set up those times to hang out and go for it.

TEACHERS

Another difficult area for a young person with CFIDS is interaction with teachers. In reality, you must prepare yourself for a possible negative reaction. There are many understanding people in the world, especially teachers, but realize that you might not have one of these people as a teacher. I don't mean to sound disparaging, but CFIDS teaches us to be realistic and accepting of the more unpleasant realities of life.

The first step in developing a beneficial relationship with your teacher is relatively simple. Be yourself. While you may be having a bad day due to your health, show them how hard you strive to learn by doing your best on all homework and tests.

The second step is more difficult if you're shy. Participate in class. This is very difficult for me, but teachers look for more than good test grades. They look for those students who show interest in their lessons. Above all, try as hard in class as you always have and your teacher will most likely see this effort, which will make it easier for you to get help later on.

One of the most important parts of receiving a good education as a YPWC is to be informed. As a person with an illness, you must research, understand, and implement your rights as a student. There is information available to discuss with your parents so that you can be your own educational advocate. (Note: The CFIDS Association of America has a variety of materials about CFIDS and education. Call 704/365-2343 for more information.)

Above all, when dealing with school officials and teachers, keep in mind that most truly do want to help you get the best possible education. If you try to achieve to your highest personal standards, they will recognize it and will often go out of their way to help you in your educational endeavors.

Part Five: HOPE

Hope: the word that keeps all of us, including those not stricken with CFIDS, going. If you are reading this article, you have demonstrated that you have hope for yourself and your health. You are trying to help yourself and those around you to understand the power of determination and hope in facing a devastating illness. As you utilize the tips you have read here for coping, there are a few basics to keep in mind.

You are a stronger, better person for having not just lived with, but triumphing over CFIDS.Although it often sounds cliché, it is true that horrible adversities, such as illness, make you stronger. By being ill, I found parts of my spirit that I never knew I had, which I used to fight my way through CFIDS. This form of inner strength lies within you also, or you would not have gotten this far. Fighting this illness separates the strong from the weak.

Some people likely have given up all hope, but simply by reading this, you have proven that you have not. This strength will make the other burdens in life less intimidating and terrifying. Also, being sick has awakened within all of us a great compassion and understanding for other people in the world who also suffer. This will benefit you not only in understanding other PWCs, but it will allow you to extend a helping hand to another human being in pain, when a lesser person might avert his gaze. Reach out to others with one hand and let the other be held by one who wishes to help you.

We always have hope and no force in the world, not even CFIDS, can dim its power to motivate us. No matter how sick you may become, never give up your sense of hope for something better. Even when you are too sick to move your limbs in bed, remember to hope. When you walk on those very limbs again, the powerful concept of hope will be more deeply etched into your spirit. When all else around is gray, remember to keep your spirit alive with hope. No matter how bad things get, keep in mind to always have that hand extended to someone else in an offering of hope and your other hand will never be far from someone who is willing to help you to your feet.

This article is distributed with the author's permission by The CFIDS Association of America.

Print Page

Close Window