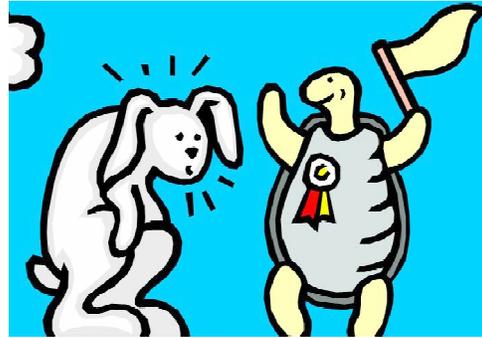


# Slow and Steady Wins the Race

This guide is intended to give ideas and to offer hope to those who suffer with Chronic Fatigue Syndrome and/or Fibromyalgia.

OFFER does not necessarily agree nor promote all the views expressed in this publication. Always consult your health care provider for advice.



## A Kid's Guide to Surviving and Succeeding in School With CFS & FMS



Organization for Fatigue & Fibromyalgia  
Education & Research

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## Tips from a Teen for Self-Advocacy at School

*Originally Published in Pediatric Network News, February 2004*

### In the Classroom:

Acquaint teachers with your needs and accommodations. A lot of people don't know much about CFIDS/FMS, so you may need to educate your teachers a little. Make an effort to form a good relationship with your teachers, and they'll probably be more than willing to help you.

Speak up. This can be difficult if you're shy, but it's essential because no one can do it for you. Learn to communicate your needs and don't hesitate to ask for something.

Don't be afraid to be different. A lot of young people are reluctant to use their accommodations because they don't want to stick out, but don't put unnecessary strain on yourself trying to be 'normal'. You'd be surprised by the number of kids who won't even notice many of the things you do.

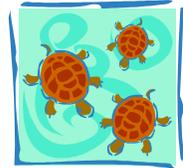
### In School Meetings:

Be prepared. Think through what you want to say beforehand. You may want to write down the things you want to discuss so you don't forget.

Take notes. With 'brain fog', it's useful to jot down what important things have been said at the meeting. Also, in certain situations it's good to have a record of your interactions with the school.

Speak up. Once again, don't be shy. Students who take interest in their own education impress people, and it's better for your school to hear about your needs from you than from your parents.

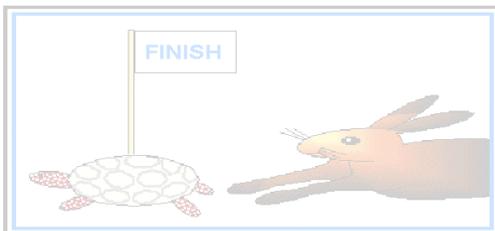
### How to Talk to Your Peers About CFS By Lauren



Explaining CFS or an unusual school schedule to your peers can be difficult. The name "Chronic Fatigue Syndrome" doesn't help, either. People identify with the word 'fatigue' and automatically assume they know what you're going through. I've received responses like, "So you just sleep in?" or "Oh...so you just sleep all the time." and "Sometimes I think I have that!" It seems that the serious, debilitating symptoms CFS causes are lost to its demeaning name. If somebody says something that seems cruel or insensitive don't take it personally. This is an illness that's hard for anybody who hasn't been personally touched by it to understand. You might want to use the opportunity to try to educate your peers a little bit. I've learned to explain that CFS feels like having mono all the time. Most kids can relate to that.

### ABOUT EXTRACURRICULAR ACTIVITY

People with CFS need to use energy wisely in order to accomplish what's most important to them. You are the only one who knows your body and it's important to pay attention to warning symptoms of over-doing it. However, it might be worth the consequence of pushing it every now and then to participate in activities you really enjoy, so long as the setback isn't too severe. I just make sure I don't overdo it during school project or test time.

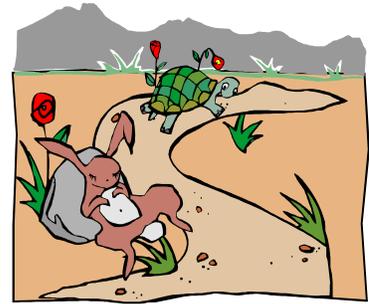


Remember that in the company of healthy peers you don't have to do everything they do. Consider limiting an outing to accommodate your needs, e.g. arrive after a dance has begun and/or leave early so you aren't as worn out. Go ahead and try out for a school play, but go for a small part, rather than a leading role. Rather than going out to the movies, rent one to watch at home with a friend. Try downhill skiing again; even making one run is better than none. This way, you can avoid feeling so isolated.

## Use Your Energy Wisely—Energy Saving Tips for YPWC Students

By Staci R. Stevens, MA

Originally published in *Youth Allied By CFIDS*, Fall 1997



Plan rest breaks. If you have to stay at school or be in class for more than an hour, talk to the teacher about taking rest breaks. Try to lie down for these rest periods. You may be able to rest in the school nurse's office. Try to rest whether you feel like it or not.

Talk to your teachers about your limitations. Use a tape recorder to tape classes. Find another student who is willing to share notes and help you with homework.

Plan your classes to correspond with your best time of day. If you feel better in the afternoons, schedule afternoon classes. If your best time is morning, schedule morning classes. (Either way, make sure to take breaks!)

Use energy-saving strategies. If you are in college, try to plan your classes in the same location or building on campus. Get handicapped parking placard and park close to the classroom.

Avoid three-hour classes if at all possible. Do not take classes for three or four consecutive hours. Schedule a one-hour class and make sure you have time to rest before your next class. If you don't live close to the campus, resting in the car is an option. The college may even be able to provide you a spare dorm room or couch for you to rest on before your next class. If you don't ask you will never know.

Take healthy snacks with you. Fruit, yogurt, bagels, skim/1% milk, juice and dried fruit make excellent snacks. Small frequent snacks help to maintain an energy balance. If you start to feel tired have a healthy snack.

Plan study time and pace yourself. Find a quiet place where you can study while reclining or lying down using a lap pillow/desk. For every 20 minutes that you study, take at least a 10-minute rest break. Plan to study when you are most alert. When reading, use a plain index card under the line of text you are reading. This will help you focus on what you are reading.

If multiple subjects overwhelm you, do them one at a time. For example, do your math homework by breaking your study time into little pieces and pacing yourself. Spend 20 minutes on the math assignment and then put it away to take a rest break and have a snack. Finish the math and move on to another subject. You will see yourself succeeding a little bit at a time, but if you make studying this way a habit, you will find that you can get more accomplished throughout the day and week.

Know your limitations and respect them. If you are invited to a party, know that you will be using physical, social and emotional energy. This is a "triple energy threat" situation. If there is a large group of people, you may have to use mental energy to focus on one conversation while a number of other conversations are going on around you. This makes going to the party the ultimate "quadruple energy threat." Plan to rest before and after the party. Know that this situation will wear you out and plan for it. If you don't feel up to using all this energy, consider saying "no thanks" to the invitation.

Alcohol, smoking and/or recreational drug use may be tempting, but can have serious side effects when combined with medications you may be taking. Alcohol is a depressant and will make you feel even sleepier than you already are. Smoking will substantially reduce your body's ability to transport oxygen, which means that you are likely to have less energy because oxygen is an energy source.

## Strategies for Learning with CFIDS

*Originally published in Youth Allied By CFIDS, Summer 1996*

*Adapted by Lauren*



### MEMORIZATION STRATEGIES

For assignments that require memorization, try breaking the assignment up in to smaller chunks to minimize mental energy expense and decrease likelihood of a resulting relapse.

Something called the serial position effect explains how this works with numbers.

For example, try reading this string of numbers and saying them out loud to yourself at the same time.

9 1 8 2 7 6 0

If you close your eyes and try to repeat that string, you will probably remember the "9 1 8" and you might get the "6 0" but the ones in the center will be the most difficult for you to remember.

If you string together "9 1 8" and then put a dash before the "2 7 6 0" it's a lot easier to process. By trimming down this series of numbers to a series of three or four, memorization is much easier.

### Cut Out Competing Stimuli

Eliminate noise and distractions as much as possible when studying. Use good study habits that apply to anybody, but know that kids with CFS/FMS may have even more need to cut out distractions that can impair concentration. For example, clear your desk of unnecessary clutter. Turn off the TV and radio. You may need to wear foam earplugs when you're trying to concentrate on reading so you can concentrate better. Make sure the room you are studying in is comfortable in temperature and has good, non-glare lighting.

### Strategies for Auditory Learning

Consider recording classes with a tape recorder, after you get permission from the school and your teachers.

Consider asking for classes to be videotaped, with permission from school and teachers.

Take notes and record your classes at the same time, then compare the information later. For a lot of people with CFS, some days you learn better by listening and other days better by reading. This way, you can optimize your learning potential.

If you miss a lot of school, or just have a hard time one day, ask the teacher or a responsible classmate for notes to that day's lesson.

When reading over your notes, try using your finger to follow the sentences, and say them out loud as you read. You're then feeding the information back to your brain using three of the five senses: touch by following the sentences with your finger, visual by reading the words and auditory by saying the information out loud. This method gives you three different ways for your brain to process the information.

### IF ANXIETY IS A PROBLEM

Worrying about performance in school, besides dealing with illness symptoms, is common for kids with CFS/FMS, as with any other chronic illness. Here are some suggestions to help.



When the teacher is handing out an exam, try putting your head down on the desk, then turn your head to the side, close your eyes and just breathe. Take a minute or two to breathe deeply and try to relax the body as much as possible.

When you're feeling tense or anxious, say to yourself, "I need to relax. I need to consciously relax my body, to breathe deeply, to close my eyes and to put myself in a better place mentally."

## More Ideas for Test Taking and Other Accommodations

Ask for extended time to complete tests and to take tests in several sessions over one or more days

Ask to take tests in a flexible setting with minimal distractions

Consider asking for a revised test format/directions such as fewer items on each page, larger print tests, or having someone read directions to you

Consider use of adaptive aids such as calculators, notes, or a tape recorder

Ask for two sets of books: One set to keep at school in your locker, and the second set to keep at home.

That way, you don't have to worry about getting too tired carrying heavy books back and forth to school

If your school is on more than one floor, ask for an elevator key

If you want to stay on track with your peers and are too sick to attend school full-time, know that you'll probably need to work on school requirements year-round. Options for this include summer school classes, independent study arranged with teachers, or on-line courses.

Remember that completing high school requirements and graduating from college takes a lot of people more than the standard four years. Allow yourself the time you need to take care of your health, save some energy for social activities, as well as to achieve academic goals.



### PLAN FOR THE FUTURE:

ACT/SAT testing You can:

--request accommodations for the normal test day (like taking breaks, stretching, bringing water, etc.).

--apply for Extended Time Testing, which allows for up to 50% more time to complete tests over several days, and allows beginning the test later than the normal 8 a.m. start time. You must have approved supervision, usually a counselor or another school official. For the extended time option, you must have documentation showing you need accommodations, and you cannot register online. Most colleges have deadlines, so be sure to plan on allotting extra time to move through the process of approval.

TEST INFORMATION:

**ACT** <http://www.act.org/aap/disab/index.html>

**SAT** <http://www.collegeboard.com/ssd/student/accom.html>

### SOME THINGS TO REMEMBER:

Even if you feel like it, you can't just stop going to public school without notifying the school district.

Legal time limits require the school to reply and to act within a certain length of time. Let them know that you feel strongly about your education, and that this isn't an issue they can ignore until you go away.

Get it in writing. The school must write and sign forms, plans, etc.

Your local school has the legal duty to educate you. They may suggest that you go to another school, and you may decide you want to transfer, but they can't force you.

If you disagree with the school's decision, you have the right to contact the school district for help. You can appeal the decision.

Your rights are not more or less than other students'. If you break the rules, you get the punishment, unless punishment would be unreasonable considering your physical limitations.

**Check information about:**

**Tax Credits** <http://www.irs.gov/pub/irs-pdf/p3966.pdf>

**SSI** <http://www.ssa.gov/notices/supplemental-security-income/>

**Medicaid** <http://health.utah.gov/medicaid/>

**Vocational Rehabilitation** <http://www.usor.utah.gov/vocrehab.htm>

Fibromyalgia is similar to Chronic Fatigue in many ways, and the suggestions mentioned so far in this guide apply to FM or (FMS), too. Here are a few more tips for surviving school with Fibromyalgia.

## Tips For Coping with FM at School

*By Erin*

One of the best tools for coping with FM symptoms is reducing stress and anxiety, which lead to pain.

A great method for achieving this is routine. Try to sit in the same place each day. This way you will have less distraction and your surroundings will be familiar to you.

Eating lunch in a quiet and comfortable place each day will give you time to relax. Teachers' classrooms or out of the way halls are good places to start.

When changing classes, take a little time to relax by practicing good posture, and releasing tension in your jaw and neck. These areas will become very tense if you have prolonged stress without a break.

While in class, be as comfortable as possible. This may seem impossible when your seat is uncomfortable, but there are ways to minimize this discomfort. A slight change of position periodically helps a lot. This is also true for any time you study, work at a computer, or write, in or out of school. Bring a lightweight jacket with you to use as a pillow or back support if needed. It will also help you keep warm if the room is chilly.



For admission, most colleges look at extracurricular like services and clubs, so start Freshman year looking for things that fit your interests and abilities. If you want and are able to start a club, no matter its size, you must have a faculty advisor.

Make sure to keep any physical strain within reason. Ask for duplicate textbooks and use several lightweight notebooks, rather than large binders. Wear comfortable shoes and clothing, and avoid wearing jewelry, especially necklaces. Though normally these things might not affect you, with the almost endless amount of strain you experience daily in school, even little things can add up.

Arrange your class schedule so you don't have so far to go between classes. Find a locker that is in close proximity to your classes.

Make plans for what you will do in school fire drills—walking down stairs or a long distance may not be not reasonable for you.

Get a note from the counselor or principal giving you permission to be in the hall after the tardy bell. Not everyone will know about your situation.

Even if you don't go to school full time, you have the right to attend school-related functions, like football games, dances, concerts, etc.

Be adamant about your accommodations. At the beginning of the year, give each teacher a letter describing your condition, and discuss this with them. Make an appointment to meet outside of class time, if possible.

If one of your teachers gives you a hard time if you need to rest your head down for a moment, remind them of your condition and any accommodations you had previously discussed with them. They are required to honor your accommodations, so don't feel bad about reminding them.

## School Options: Learn Your Rights *By Carol*

Ideally, you and your school will work together toward the common goal of helping you to succeed despite the limitations of your illness. However, expect that some conflicts may arise. Hopefully, the tips in this section will make it easier for you to secure your rights at school.

If you want to graduate, you will have to work with the Utah UPass program and the No Child Left Behind requirements. If you have a written form explaining what the school is required to do, as well as what *you* are required to do, things will go much smoother. You will need to consider the fact that different schools have different support in funding, staff, and confidence in some programs over others.

You must also be honest about what matters most to you. Even if you can't arrange the perfect school situation, you can strive to accomplish what matters most to you, whether it is graduation, or experiences with friends, art, music, etc.

Each local school should have an administrator who is assigned to assist students with special needs, and counselors to help. Identifying these people should be your first step. However, some school employees don't understand CFS or FM, or don't think the needs of one person are worth the effort. They are unsure of what they are allowed to do. They might not even know who to contact for advice. School districts have staff who will know more about how to help, but may not know enough details about the local school to know how to help. You may have to be your own advocate to get the local school and school district working together.

### **LEARN YOUR RIGHTS:**

Study the laws related to Section 504 and Special Education, or meet with someone in your school district who can explain the laws to you. There are lots of sites online. Schools could lose their Federal funding if they don't follow the laws.

Your doctor's medical diagnosis will be considered, along with any aptitude and achievement tests, school records, teacher recommendations, in deciding if you have a disability which "substantially limits a major life activity."

### **LEARN YOUR OPTIONS:**

#### **Choices:**

Neighborhood school

Transfer to a different school

Home school under supervision of the school district

Home school with permission of the school district

Online school with permission of the school district



#### **Plans:**

504 Plan : Section 504, a federal law designed to protect the rights of individuals with disabilities, requires a school district to provide a "free appropriate public education" to each student with a disability who is in the school district, regardless of the nature or severity of the disability--meaning provision of regular or special education and related aids and services designed to meet each student's needs.

IEP Plan--category "Other Health Impaired": Individual Education Plans, are for Special Education students such as deaf, blind, learning disabled, mentally handicapped, or those whose medical problems prevent them from regular school attendance. Public Law 94-142 is over 30 years old, so more people are familiar with it. Few have had experience with health impaired services. Some students don't like the label of "special education," but if it helps you accomplish your goals, it's worth it.

Electronic High School <http://ehs.uen.org>

EHS is free, fully accredited, and you can work at your own pace. To enroll, you must first meet with your school counselor. When you complete a course, the grade is sent to your school. Some classes are better than others and some require more work than others. They must make accommodations, just as any other public school, but they will need suggestions about what you need.

GED (General Equivalency Diploma) Test <http://www.usoe.k12.ut.us/adulted/home.htm>

If you are 18 years old and your senior class has graduated, you may take the GED Test at any time. If you are 17 or 18 years old and your senior class has **not** graduated, you are required to submit a letter from the school indicating you are not regularly enrolled in school and a letter from your parent or legal guardian authorizing that you take the GED test. Public libraries have classes to prepare for the test.

## Books for Pediatric CFIDS in General



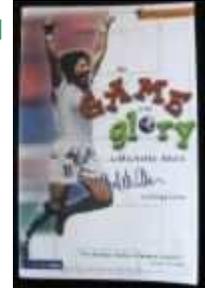
### Zoe's Win

By Jane Colby

This book demonstrates the nature of the illness itself, and shows young people how it is possible to adapt and win through. Further sections of the book provide essential information for doctors, teachers, young people and their families.

### The Game and the Glory By Greg Lewis and Michelle Akers

This is the inspirational story of Michelle Akers, a member of the thrilling 1999 U.S. Women's World Cup championship soccer team, who battled phenomenal odds to triumph on the field and in her faith. Her award-filled career, including the physical, personal, and spiritual struggles she has overcome, is the subject of this book.



### Standing Fast By Michelle Akers, Tim Nash (Introduction)

A chronicle of Michelle Akers' battle with Chronic Fatigue Syndrome.

### Face To Face by Michelle Akers with Judith A. Nelson

This book covers the continuous tribulations that Akers has faced through her life as she strove to become the best woman soccer player in the world. It describes the highs and lows of her personal life, her ongoing fight against chronic fatigue syndrome, and how Christianity gave her renewed hope and strength.



### A Parent's Guide to CFIDS

By David Sheffield Bell, Mary Z. Robinson, Jean Pollard, Tom Robinson, Bonnie Floyd



Examines how CFIDS negatively affects a child's health, education, and development and what can be done to alleviate pain and discomfort of this illness. If you have a child with CFIDS, this book will be an invaluable guide as you help your child deal with the frustration and loneliness that typically accompanies this illness and as you advocate for and support your child in school. Questions about dealing with friends and

setting activity limits are addressed, with an especially strong chapter that helps parents understand the feelings that a young person with CFIDS experiences.

### Adolescence and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome:

#### Journeys with the Dragon By Nadia Edgar Brotherston

The Calgary Women's Emergency Shelter, Canada. An examination of the testimonials of four teenage sufferers of chronic fatigue syndrome, offering a survival guide for patients and parents and insight for health care professionals.



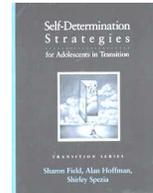
### Finding Strength in Weakness: Help and Hope for Families Battling Chronic Fatigue Syndrome By Lynn Vanderzalm

Chronic Fatigue Immune Deficiency Syndrome (CFIDS) is a debilitating, incurable illness that hijacks the body's immune system and drains the life out of its victims, often leaving them incapacitated for years. Vanderzalm shares her family's struggles and questions--along with those of 70 other men, women, and children-- while offering direction, encouragement, and hope to the countless families who battle with CFIDS.

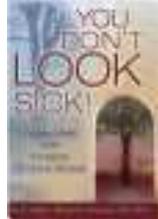
## More Books

### **Self-Determination Strategies for Adolescents in Transitions**

**(Pro-ed Series on Transition)** By Sharon Field, Alan Hoffman, Shirley Spezia  
This book provides practical strategies for promoting self-determination in school settings, which is a critical component of the transition process.



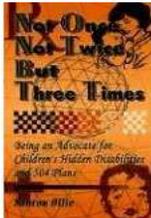
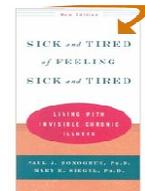
### **You Don't LOOK Sick!: Living Well With Invisible Chronic Illness**



By Joy H. Selak, Steven S. Overman  
This Book chronicles a patient's true-life accounts and her physician's compassionate commentary as they take a journey through the three stages of chronic illness—Getting Sick, Being Sick, and Living Well. This resource helps you focus on building a meaningful life that contains illness as opposed to a life of frustration and fear. Designed for patients in at all stages of the chronic illness journey, this book will also be illuminating for caregivers and loved ones.

### **Sick and Tired of Feeling Sick and Tired: Living with Invisible Chronic Illness, Second Edition**

By Paul J Donoghue, Mary Elizabeth Siegel  
Donoghue and Siegel direct their book to healthcare providers, families, and patients dealing with invisible chronic illness (ICI)--those conditions that are chronic and disabling but not readily apparent to the casual observer.



### **Not Once, Not Twice, but Three Times: Being an Advocate for Children's Hidden Disabilities and 504 Plans**

By Sahron Ollie  
This guide identifies hidden disabilities, symptoms and behaviors to look for, and how a parent can become an advocate for their child with such a disability.

## ONLINE RESOURCES

-OFFER Organization For Fatigue & Fibromyalgia Education and Research Site

<http://www.offerutah.org/>

-The New Jersey Chronic Fatigue Syndrome Association CFS CFIDS Support Group

<http://www.njcfsa.org/>

-The Pediatric Network for Chronic Fatigue Syndrome, Fibromyalgia, and Orthostatic Intolerance <http://www.pediatricnetwork.org/>

-CFIDS Youth Site <http://www.cfids.org/youth.asp>

-*More Than Me* is aimed at young people with ME/CFS/CFIDS and friends or family of sufferers. <http://klik.to/morethanme>

*Independent study on-line courses are offered through the following:*

-BYU Independent Study <http://ce.byu.edu/is/site/>

-Utah Electronic High School <http://www.ehs.uen.org/>

### ***Other Resources:***

#### **Utah Dept of Education**

250 E. 500 South or mail to PO Box 144200

Salt Lake City, UT 84114

Phone 801-538-7500 <http://www.schools.utah.gov/>

