

# **TEACH-ME:**

**A SOURCEBOOK FOR TEACHERS OF YOUNG PEOPLE**

with

**Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)**

**and Fibromyalgia Syndrome (FMS)**

with

**Dr. David S. Bell**

**world authority and researcher on ME/CFS and FMS  
in young people**

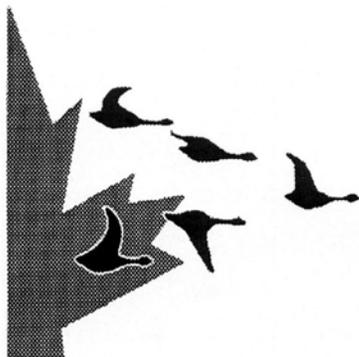
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**lead author of the Canadian ME/CFS Consensus Document  
Co-Editor of the Canadian FMS Consensus Document**

and the

**TEACH-ME Task Force**

**Second Edition**



**NATIONAL**

**ME / FM**

**ACTION NETWORK**

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*Order Form for TEACH-ME: Sourcebook, and Membership Application are at the end of book.*

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**National ME/FM Action Network**

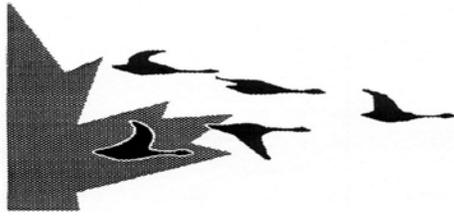
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NATIONAL  
**ME / FM**  
ACTION NETWORK

is a Canadian, registered, non-profit organization dedicated to advancing the recognition and understanding of Myalgic Encephalomyelitis / Chronic Fatigue Syndrome and Fibromyalgia Syndrome through education, advocacy, support and research.

**Our Motto:**

*"People helping people help themselves."*

**Dear Educators,**

**We can help you!** Please visit our website: <http://www.mefmaction.net> Of particular interest is our "Youth Site", which includes sections for parents and teachers. We think you will find it informative. Our Youth Site also has a "Young Writers" section where we post poems and short stories written by young people with FMS or ME/CFS. The guidelines for submissions are on our website. Please encourage students with ME/CFS or FMS to submit their poems or short stories. It is rewarding for these young people to have their writing posted on a National Website.

If you have developed or discovered tips or techniques that are helpful in assisting students with ME/CFS or FMS, we would be most pleased to hear from you. Suggestions on how we can make more educators aware of *TEACH-ME: A Sourcebook for Teachers of Young People with Myalgic Encephalomyelitis (ME/CFS) and Fibromyalgia Syndrome (FMS)* are welcome. Teaching tips and student submissions should be sent to Marj van de Sande (Topic: Youth Site) at [mvandes@shaw.ca](mailto:mvandes@shaw.ca)

The National ME/FM Action Network has developed a number of educational resources. Our Membership Form and a list of available resources are at the end of this book. There is also an order form for additional copies of *TEACH-ME: A Source Book for Teachers of Young People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) and Fibromyalgia (FMS)*.

Please help us help those with ME/CFS and FMS by becoming a member or making a donation. Our membership is only \$25.00 a year and includes our quarterly newsletter, "Quest", with original articles by doctors, researchers, and lawyers. Members are able to download their newsletter from the secure "Members Only" area of our website. This area also includes our "Quest Library" and research abstracts.

Thank you for the interest in assisting students with FMS and ME/CFS.

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*Our logo, Canadian geese flying in formation,  
portrays working cooperatively and supporting each other.*

## THE GOOSE STORY

Next fall, when you see geese heading south for the winter... flying along in a "V" formation, you might consider what science has discovered.

As each bird flaps its wings, it creates an uplift  
for the bird immediately following.

By flying in "V" formation the whole flock adds  
at least 71% greater flying range,  
than if each bird flew on its own.

*People who share a common direction and sense of community  
can get where they are going more quickly and easily,  
because they are traveling on the thrust of one another.*

When a goose falls out of formation, it suddenly feels the drag and resistance of  
having to go it alone and quickly gets back into formation to take advantage of the  
lifting power of the bird in front.

*If we have as much sense as a goose,  
we will stay in formation with those who are headed the same way we are.*

When the head goose gets tired it rotates back in the wing  
and another goose flies point.

*It is sensible to take turns doing demanding jobs with people  
or with geese flying south.*

Geese honk from behind to encourage those up front to keep up their speed.

*What do we say when we honk from behind?*

Finally, and this is important, when a goose gets sick,  
or is wounded by gunshots, and falls out of formation,  
two other geese fall out with that goose  
and follow it down to lend help and protection.

They stay with the fallen goose until it is able to fly or until it dies;  
and only then do they launch out on their own  
or with another formation to catch up with their group.

*If we have the sense of a goose, we will stand by each other like that!*

*Author Unknown*

## About the Contributors

### Medical Authorities

**David S. Bell, MD, FAAP**, is a world authority in ME/CFS and FMS in young people and adults. He previously taught pediatrics at Harvard Medical School. The U.S. Department of Health and Human Services appointed Dr. Bell Chairman of the Chronic Fatigue Syndrome Advisory Committee, which will provide expert advice/recommendations regarding diagnosis, treatment, risk factors and educational programs related to the illness. Dr. Bell is on the Board of Directors of the American Association for Chronic Fatigue Syndrome and editor of their newsletter. He also serves on the Editorial Board of the *Journal of Chronic Fatigue Syndrome*.

Dr. Bell has published papers in leading medical journals and authored several books on CFS. A highly sought international speaker, he has given hundreds of lectures on ME/CFS at medical conferences. Dr. Bell was co-chair of the Childhood Chronic Fatigue Syndrome Symposium of the International Conference on Fatigue Science 2005, held in Tokyo. His present areas of research in ME/CFS are the autonomic nervous system, the role of ADHD and blood volume, orthostatic intolerance, and the education of children and youth. Dr. Bell has been listed in both the Marquis and Sterling *Who's Who in America*.

**Bruce M. Carruthers, MD, CM, FRCP(C)**, is one of Canada's best known authorities of ME/CFS and FMS. Dr. Carruthers is the lead author of the Canadian ME/CFS Consensus Document and Co-Editor of the Canadian FMS Consensus Document. He is a specialist in Internal Medicine with a particular interest in chronic fatigue states, chronic pain problems and health enhancement. Dr. Carruthers was a Clinical Instructor and Assistant Professor at the U.B.C. program of Internal Medicine for fifteen years.

Dr. Carruthers has authored numerous articles and given many lectures and international seminars on ME/CFS and FMS. He was a Medical Research Council Fellow and researcher at the University of British Columbia. His present areas of research are on the dynamics of brain function, space perception, and cognitive fatigue in ME/CFS patients. Dr. Carruthers has a devoted interest in and dedication to the study and care of patients with ME/CFS and FMS. Dr. Carruthers is Medical Advisor to the National ME/FM Action Network.

### TEACH-ME Task Force

**Kate Andersen** is a university educator and researcher, a writer, advocate, and parent counsellor. She formerly was Youth Consultant to the National ME/FM Action Network. She has had ME/CFS and FMS since 1983 and is the parent of three young adults.

**Tigist Amdemichael** is a teacher with the Toronto District School Board. She has degrees in biochemistry, psychology and education and teaches high school sciences.

**Diane Dawber** is an internationally recognized author of poetry for children and books on health issues. She taught for many years at levels ranging from junior kindergarten to university and adults. Diane is the author of a book on Fibromyalgia.

**Mary Ellen** formerly was the Manager of Special Projects for the National ME/FM Action Network, and Chairperson of the TEACH-ME Task Force. She was a secondary teacher, who is now disabled with ME/CFS.

**Teresa Hitch** taught special education, art, math, and English as a second language in public schools, and art at the college level. She was a contributing editor to the National Association of Secondary School Principals' text on mathematics study skills.

**Aldene Mason** is a parent with a background in adult education and management training. She worked closely with the Alberta Special Education review and has extensive experience working with school teachers and personnel.

**Margaret Parlor** is Advisor on Youth Issues to the National ME/FM Action Network. She has a background in data analysis, writing/editing information materials for the public, and is the parent of three young people. She contributed to the section on home tutoring.

**Mary Robinson** is an American educator and research assistant to Dr. David S. Bell. She is co-author of a book and a research study with Dr. Bell. Mary is co-founder of the Pediatric Network for CFS, FMS, and OI (Orthostatic Intolerance), which is a website and forum dedicated to issues that families and children with these illnesses face. (See Appendix 2) Mary counsels parents on how to work with their schools to get the best educational plan for their children, and offers support and coping tips for the day to day trials of children living with these illnesses. Mary has three children, two of whom have been stricken with ME/CFS.

**Marjorie van de Sande** taught kindergarten through grade six and secondary home economics. Her graduate studies' major in education was early childhood; her passion was teaching children to read. She also taught ballet, coached rhythmic gymnastics, and did choreography. Marjorie contributed to and was Consensus Coordinator for both the Canadian ME/CFS and FMS Consensus Documents. She is Advisor to the National ME/FM Action Network and is our webmaster. Formerly she was our Director of Education. Marjorie is Editor of the *Legal Disability Manual for Fibromyalgia Syndrome and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome* and has authored numerous articles on ME/CFS and FMS. She has had ME/CFS and FMS for more than twenty years. Marjorie is a parent and grandparent.

## Parents and Young People

**The parents** of Emilie, Erin, Jacob, Karen, Marc, Michael, Stephanie, Stuart, and Su Lin

**Courageous Young People:** Emilie, Erin, Jacob, Karen, Marc, Michael, Stephanie, Stuart, and Su Lin - who shared their stories about living with ME/CFS and/or FMS through their parents, or in their own words.

## Dedication of Book

To Lydia, our "Mom" and "Teacher" at the Network, from all of us, with love, gratitude, and admiration.

## **Mission Statement**

The purpose of this book is to enhance educators' understanding of the unique educational needs of children and adolescents with ME/CFS and FMS. Our aim is to assist teachers in developing modifications to educational plans and curriculum. Other school personnel may also find this information helpful. This book is not meant to replace contact between school personnel and the student and her/his family, which is essential immediately following the diagnosis of ME/CFS and/or FMS and at the beginning of each school year. Medical advice should be sought from an appropriately qualified physician.

## **Introduction to First Edition**

By

**Mary Ellen**

Chairperson, TEACH-ME Task Force, National ME/FM Action Network

Canadian teachers are becoming more aware of children and adolescents with ME/CFS and/or FMS. It has not always been this way, partly because ME/CFS and/or FMS have had a controversial history. Although the number of adults being diagnosed with these illnesses seemed to grow rapidly in the mid-eighties, official recognition of the illness in adults has been slow. Tragically, recognition of the prevalence and devastation of ME/CFS and/or FMS in children has been even slower, leading to many heartbreaking situations. Fortunately, all that is changing. Research on ME/CFS and/or FMS has been increasing rapidly, including research on children and adolescents. We can expect that in the next few years we will understand these illnesses much better - in people of all ages. While we are waiting for that new knowledge, there is much that the classroom teacher can do for the young person diagnosed with ME/CFS and/or FMS.

The authors are Canadian teachers, disabled with ME/CFS and/or FMS, who are members of the National ME/FM Action Network. We developed a unique e-mail conference, known as TEACH-ME, in which we discussed ways that children with ME/CFS and/or FMS could be provided with an uninterrupted education. As people with ME/CFS and/or FMS ourselves we were devastated to imagine the effects of ME/CFS and/or FMS on young people. As teachers, we remained unwaveringly committed to providing education to all children, no matter how ill or disabled. Yet, as adults who were homebound by the illness, we knew this could not be an easy task for the young person or for the classroom teacher. We wanted to use our combined expertise in teaching and experience of the illnesses to help these courageous youngsters.

We were very privileged to have the consultation of Dr. David S. Bell and Mary Z. Robinson. Dr. Bell is a renowned paediatrician and the leading researcher on ME/CFS and/or FMS in children. Ms. Robinson is a US educator, research assistant to Dr. Bell, co-author of "A Parent's Guide to CFIDS", and parent of two young people with ME/CFS and FMS. Our collaboration with Dr. Bell and Ms. Robinson enabled us to link our personal experiences and teaching expertise with the most up-to-date and sound international research knowledge. As well, Dr. Bell's and Ms.

Robinson's knowledge of ME/CFS and FMS is unique in that it has been acquired from following real families and children coping with this illness over many years.

We are also greatly indebted to, and make much use of, the pioneering work of Jane Colby, Executive Director of Tymes Trust, former head teacher and Consultant for the Education of Children with ME, and author of two books on ME and of numerous papers and articles. She is a member of the UK government Chief Medical Officer's Working Group on CFS/ME. We also wish to give credit to the other members of that Working Group for their publication, "Childhood ME", as well as to the CFIDS Association of America and the National CFIDS Foundation for their advocacy and their excellent materials on education of young people with ME/CFS and/or FMS. The research of Dr. Richard L. Bruno, Director of the Fatigue Management Program at Englewood Hospital, New Jersey, and Chairman of the International Post Polio Task Force, and of Dr. Elizabeth Dowsett, the leading British ME researcher, has been very inspiring.

We also thank the teachers and researchers who read the drafts and gave us valuable feedback. Special mention goes to Dorothy Morris, Ph.D. candidate and ME/CFS researcher, at Deakin University in Australia. She spent a great deal of time evaluating the first draft and making numerous helpful suggestions. We thank Jill Moss, from AYME in the United Kingdom, for permission to reproduce her Ability Scale in this Sourcebook and Vicki Walker of the CFIDS Association of America for providing us with some of the research reports reviewed.

While we give credit to all of the above for the merits of this Sourcebook, we must take responsibility for any shortcomings in it. As well, this Sourcebook is definitely "standing on the shoulders of giants", and builds on the pioneering work of many people, a large number of whom came out and defended the rights of children with ME/CFS and/or FMS at a time when it was very difficult to do so. If we have failed to acknowledge any of them here or throughout the Sourcebook, we apologise.

### **The Voices of Young People with ME/CFS and/or FMS and their Parents**

Young people with ME/CFS and/or FMS, and their families, made special contributions by sharing their real experiences. We thank them enormously for enriching this project.

# Introduction to Second Edition

By

**Margaret Parlor**

Advisor on Youth Issues, National ME/FM Action Network

Subsequent to the publication of the first edition of TEACH-ME, clinical diagnostic definitions for myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and fibromyalgia syndrome (FMS) have been published. As these Consensus Documents are gaining national and international prominence, we are pleased to include the clinical criteria in our second edition. The clinical criteria and a discussion of the prominent symptoms of ME/CFS are presented in chapter one and those for FMS are presented in chapter two.

In response to a questionnaire sent to doctors across Canada asking what items would best assist them in the diagnosis and treatment of ME/CFS and FMS, the National ME/FM Action Network spearheaded the drive for clinical diagnostic and treatment protocols for these illnesses. The Network approached Dr. Bruce M. Carruthers of British Columbia and Dr. Anil Kumar Jain of Ontario, experts in these illnesses, who kindly consented to write draft documents. Lydia Neilson, our President, presented the draft documents to the Minister of Health. Panels of international experts, which included both clinicians and researchers in ME/CFS and FMS, were selected by Health Canada. Marjorie van de Sande, formerly the Director of Education to the National ME/FM Action Network, worked with both panels on the documents as Consensus Coordinator. After the Consensus Documents went through revisions, the final documents received 100% consensus by the Expert Panels.

Many adults find it difficult to explain their symptoms of ME/CFS. Young people, who generally do not have the communication skills of adults, may find it more difficult to articulate their symptoms. In addition, there is no clear baseline to which changes can be compared as the physiology of young people is constantly changing. Children are expected to be healthy and they may not be aware that their symptoms are abnormal. Symptoms in teenagers may be dismissed as teenage rebellion or psychological problems. Those who persist in the reality of their symptoms may be incorrectly labelled with Somatization Disorders, such as Hypochondriasis or Conversion Disorder. Some parents who support their children may be accused of encouraging their children to be ill, and in rare cases they have been investigated by child protection agencies.

In the fable, *"The Blind Men and the Elephant"*, one blind man felt the tail and thought it was a rope; another touched a tusk and thought it was a spear, and so forth. Because each blind man focused on one feature of the elephant, they did not recognize the essence of the whole animal. Sometimes a young person does not realize that their symptoms are not normal, particularly if the onset of ME/CFS is gradual. It is easy for parents to focus on one or two symptoms that are most troublesome for their child, and overlook other symptoms. The multifaceted, yet distinctive pattern of symptoms in ME/CFS may be more noticeable to alert educators, who have the advantage of observing many students on a daily basis, than it is to parents of one or two children. If a teacher does observe a student who exhibits a number of these symptoms, s/he should meet with the parents to discuss the student's difficulties.

It is hoped that the Clinical Diagnostic Criteria will assist readers in understanding these illnesses and the impact they can have on young people.

## Chapter 1

# Understanding Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome in Young People

By

**Marjorie I. van de Sande**, B. Ed, Grad. Dip. Ed.  
Consensus Coordinator for the Canadian ME/CFS Consensus Document  
National ME/FM Action Network, Advisor

**Bruce M. Carruthers**, MD, CM, FRCP(C)  
Lead author of the Canadian ME/CFS Consensus Document  
National ME/FM Action Network, Medical Advisor

## Introduction

Educators who encounter students with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) are often perplexed by the many, varied symptoms, and the degree of disability they can cause. In order to give educators a better understanding of ME/CFS, this chapter includes the Clinical Diagnostic Criteria, a summary of common symptoms, and some educational implications.

### What is ME/CFS?

Myalgic Encephalomyelitis (ME), which is also called Chronic Fatigue Syndrome (CFS) in some countries, will be referred to as ME/CFS throughout this chapter. It is an acquired illness that affects all body systems; predominantly the neurological, immune, and endocrine systems. It is classified as a neurological illness in the World Health Organization's International Classification of Diseases. Chronic fatigue, which is a symptom of many chronic illnesses, must not be confused with ME/CFS as severe fatigue is only one of numerous criteria. As is the case in all illnesses, the severity of ME/CFS varies but it can be severely debilitating.

### What Causes ME/CFS?

In many cases ME/CFS begins with a flu-like illness or upper respiratory infection. Instead of the flu or respiratory infection going away, a cluster of other symptoms gradually appears (1). Research has confirmed that there is often a breakdown in one of the body's immune system defense pathways (2,3). The rapid and often dramatic deterioration in functioning makes these cases easier to diagnose. Immunization, anesthetics, physical trauma, and exposure to environmental pollutants, chemicals and heavy metals have preceded the onset of ME/CFS in some patients. In other cases the onset is gradual with no obvious cause, making these cases more difficult to diagnose in a timely fashion. More than one member of a family may be afflicted with ME/CFS suggesting that there may be a genetic component in some cases besides infectious causes.

### Who Gets ME/CFS?

ME/CFS affects all age groups, including children, all racial/ethnic groups, and all socioeconomic strata(4,5). ME/CFS affects both sexes but it is more prevalent in females. Females have smaller hearts, lower blood volume, and produce fewer red blood cells than males. As red

blood cells carry oxygen and nutrients to the tissues and pick up waste and toxins to be eliminated, females may have a lesser ability to cope with pathogens and toxins.

### **What is the Natural Course of ME/CFS?**

ME/CFS tends to plateau between six months and six years. While studies(6,7,8) indicate that less than 10% of adults return to their pre-illness level of functioning, the prognosis for children is much better. A thirteen year study(9) of children and adolescents with ME/CFS indicated that approximately 80% had satisfactory outcomes. 37% were symptom-free and 40% had symptoms that persisted in mild to moderate forms. Generally children who have milder symptoms are more likely to recover, but the prognosis of an individual case cannot be predicted with certainty. Even if a person recovers or the ME/CFS is in remission, care must be taken to not exceed her/his activity boundaries as relapses can occur several years later.

### **What is the Difference between ME/CFS and Fibromyalgia Syndrome (FMS)?**

There is a large overlap of the symptoms of ME/CFS and FMS and many think they may be variants of a similar disease process. FMS, which has a much greater population incidence, is often triggered by physical trauma and pain is the most prominent feature, indicating that there is more impairment of the function of muscles, ligaments and tendons. ME/CFS is commonly triggered by a viral infection and there is more severe fatigue and prolonged post-exertional malaise. There is likely to be more pronounced dysfunction of cognitive abilities and the other body systems. The research test for deregulation of an antiviral defense pathway can distinguish ME/CFS patients from FMS patients (2). Those who meet both criteria test the same as those who just have ME/CFS.

## **Clinical Definition of ME/CFS**

The International Expert Consensus Panel, selected by Health Canada, consisted of eleven doctors who were actively diagnosing/treating ME/CFS and/or were researchers in this illness. Collectively they had diagnosed and/or treated more than 20,000 ME/CFS patients. There was 100% consensus among panel members on the final document. The Clinical Definition encompasses the broad cluster of symptoms and signs that give ME/CFS its distinctive character.

<b>CLINICAL WORKING CASE DEFINITION OF ME/CFS</b>
<i>A patient with ME/CFS will meet the criteria for fatigue, post-exertional malaise and/or fatigue, sleep dysfunction, and pain; have two or more neurological/cognitive manifestations and one or more symptoms from two of the categories of autonomic, Neuroendocrine, and immune manifestations; and adhere to item 7.</i>
<b>1. Fatigue:</b> The patient must have a significant degree of new onset, unexplained, persistent, or recurrent physical and mental fatigue that substantially reduces activity level.
<b>2. Post-Exertional Malaise and/or Fatigue:</b> There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post exertional malaise and/or fatigue and/or pain and a tendency for other associated symptoms within the patient's cluster of symptoms to worsen. There is a pathologically slow recovery period - usually 24 hours or longer.
<b>3. Sleep Dysfunction:*</b> There is unrefreshed sleep or sleep quantity or rhythm disturbances such as reversed or chaotic diurnal sleep rhythms.

**4. Pain:**\* There is a significant degree of myalgia. Pain can be experienced in the muscles, and/or joints, and is often widespread and migratory in nature. Often there are significant **headaches** of new type, pattern or severity.

**5. Neurological/Cognitive Manifestations:** **Two or more** of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances – e.g. spatial instability and disorientation and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload<sup>1</sup> phenomena: cognitive, sensory – e.g. photophobia and hypersensitivity to noise - and/or emotional overload, which may lead to “crash”<sup>2</sup> periods and/or anxiety.

**6. At Least One Symptom from Two of the Following Categories:**

- a) **Autonomic Manifestations:** orthostatic intolerance - neurally mediated hypotension (NMH), postural orthostatic tachycardia syndrome (POTS), delayed postural hypotension; light-headedness; extreme pallor; nausea and irritable bowel syndrome; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmias; exertional dyspnea.
- b) **Neuroendocrine Manifestations:** loss of thermostatic stability – subnormal body temperature and marked diurnal fluctuation, sweating episodes, recurrent feelings of feverishness and cold extremities; intolerance of extremes of heat and cold; marked weight change - anorexia or abnormal appetite; loss of adaptability and worsening of symptoms with stress.
- c) **Immune Manifestations:** tender lymph nodes, recurrent sore throat, recurrent flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

**7. The illness persists for at least six months. It usually has a distinct onset, \*\* although it may be gradual.** Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

**To be included, the symptoms must have begun or have been significantly altered after the onset of this illness. It is unlikely that a patient will suffer from all symptoms in criteria 5 & 6. The disturbances tend to form symptom clusters that may fluctuate and change over time. Children often have numerous prominent symptoms but their order of severity tends to vary from day to day.**

**\*There is a small number of patients who have no pain or sleep dysfunction, but no other diagnosis fits except ME/CFS. A diagnosis of ME/CFS can be entertained when this group has an infectious illness type onset.**

**\*\*Some patients have been unhealthy for other reasons prior to the onset of ME/CFS and lack detectable triggers at onset and/or have more gradual or insidious onset.**

**Exclusions:** Exclude **active** disease processes that explain most of the major symptoms of fatigue, sleep disturbance, pain, and cognitive dysfunction. It is essential to exclude certain diseases, which would be tragic to miss: Addison's disease, Cushing's Syndrome, hypothyroidism, hyperthyroidism, iron deficiency, other treatable forms of anemia, iron overload syndrome, diabetes mellitus, and cancer. It is also essential to exclude treatable sleep disorders such as upper airway resistance syndrome and obstructive or central sleep apnea; rheumatological disorders such as rheumatoid arthritis, lupus, polymyositis and polymyalgia rheumatica; immune disorders such as AIDS; neurological disorders such as

<sup>1</sup> “Overload” refers to hypersensitivities to various types of stimuli that have changed from pre-illness status.

<sup>2</sup> “Crash” refers to a temporary period of immobilizing physical and /or mental fatigue.

multiple sclerosis (MS), Parkinsonism, myasthenia gravis and B12 deficiency; infectious diseases such as tuberculosis, chronic hepatitis, Lyme disease, etc.; primary psychiatric disorders and substance abuse. *Exclusion of other diagnoses, which cannot be reasonably excluded by the patient's history and physical examination, is achieved by laboratory testing and imaging. If a potentially confounding medical condition is under control, then the diagnosis of ME/CFS can be entertained if patients meet the criteria otherwise.*

**Co-morbid Entities:** Fibromyalgia Syndrome (FMS), Myofascial Pain Syndrome (MPS), Temporomandibular Joint Syndrome (TMJ), Irritable Bowel Syndrome (IBS), Interstitial Cystitis, Irritable Bladder Syndrome, Raynaud's Phenomenon, Prolapsed Mitral Valve, Depression, Migraine, Allergies, Multiple Chemical Sensitivities (MCS), Hashimoto's thyroiditis, Sicca Syndrome, etc. *Such co-morbid entities may occur in the setting of ME/CFS. Others such as IBS may precede the development of ME/CFS by many years, but then become associated with it. The same holds true for migraines and depression. Their association is thus looser than between the symptoms within the syndrome. ME/CFS and FMS often closely connect and should be considered to be "overlap syndromes".*

**Idiopathic Chronic Fatigue:** If the patient has unexplained prolonged fatigue (6 months or more) but has insufficient symptoms to meet the criteria for ME/CFS, it should be classified as idiopathic chronic fatigue.

Carruthers BM, Jain AK, De Meirleir KL, Peterson DL, Klimas NG, Lerner AM, Bested AC, Flor-Henry P, Joshi P, Powles ACP, Sherkey JA, van de Sande MI. **MYALGIC ENCEPHALOMYELITIS / CHRONIC FATIGUE SYNDROME: Clinical Working Case Definition, Diagnostic and Treatment Protocols.** *Journal of Chronic Fatigue Syndrome* 11(1):7-116, 2003. © Copyright 2003, Haworth Press Inc., Journal of Chronic Fatigue Syndrome, 10 Alice Street, Binghamton, NY 13904-1480, USA, **reprinted with permission.** (The Consensus Document may be viewed on our website and instructions for ordering it are available on our website <http://www.mefmaction.net> )

## Symptoms and Signs of ME/CFS

To those who are not alert to signs and symptoms of ME/CFS, the patient does not look particularly ill and consequently may not be believed. Dr. David Bell, a renowned authority on ME/CFS in both children and adults, stated, "The question should not be 'How can someone who looks well be so ill?' but rather it should be, 'How can someone who is so ill possibly look well?' "(10).

### 1. Fatigue

'Fatigue' may be an inappropriate word to use in reference to ME/CFS as it is not the kind of fatigue that healthy people experience. The 'fatigue' experienced in ME/CFS is more aptly described as a combination of exhaustion and weakness that can be overwhelming.

The fatigue of young people with ME/CFS is significant, has different characteristics from normal fatigue, and must not be taken lightly. Patients usually have a combination of pathophysiological fatigues that adversely affects both their physical and cognitive functioning. There is arousal fatigue due to their poor sleep quality and sometimes quantity. Oxygenation fatigue is caused by the inability to deliver sufficient oxygen to the tissues and brain. There may be metabolic fatigue where the cells are unable to transform the substrates of energy into useful functions. If they also have fibromyalgia syndrome, as many have, they will have muscular fatigue and may also have structural fatigue (11). Healthy people have energy reserves that they can draw upon when they push themselves and are refreshed by a good night's sleep. People with ME/CFS have exhausted their

energy reserves. They can be doing an activity and then suddenly, rapidly “crash”, with a dynamic similar to a punctured balloon. Their energy is simply gone. It is essential that educators be aware that these students can have serious medical repercussions if they exceed their activity boundary limits.

Dear reader, have you ever had a case of flu that was so severe that you slept all day and every time you tried to get up, you were so weak that you had an urgent need to lie down? That is what the acute stage of ME/CFS is like but it can extend for months or years. A simple activity, such as taking a shower, can be so exhausting that you have to go back to bed. Some patients are so severely affected that they are bedridden for years and are dependent on others for their care. While these patients are too ill to attend school, it is important that all educators be cognizant of the devastating effects ME/CFS can have on young people.

The mother of a severely affected young person describes the impact of ME/CFS on her daughter as follows:

Stephanie became ill just after her 13<sup>th</sup> birthday and is now 17 years old. She has suffered severe abdominal pain every day for four years, which worsens with minimal physical or mental exertion. Other symptoms, including severe weakness and orthostatic intolerance, cause her to be very unsteady walking and she frequently collapses when standing. She is wheelchair bound on the rare occasion that she has an outing. Stef has become uncoordinated, causing her to knock things over or spill things, and cannot lift a jug of water to pour herself a drink. Stef cannot bathe, wash herself, or brush her teeth without my assistance and these activities bring on post-exertional malaise. In spite of being very intelligent, as her condition deteriorates she has increasing difficulty in understanding what people are saying. An enormous distress to her is that she loves reading but does not have the strength to read for any length of time and is too weak to hold a book. The effect of ME/CFS on Stef has been devastating! It never ceases to amaze me that Stef has maintained her courage, kept her sense of humour, and has a deep compassion for others.

People, who have milder cases or are in the chronic stage of ME/CFS, usually have some periods of time during the day when they can function but not at the level that they did before they became ill.

According to the Clinical Definition, fatigue must be severe enough to reduce activity level substantially, generally by 50% or more. Young people are usually alert and active for 12 to 14 hours a day; thus the activity level of young people with ME/CFS would be a maximum of six or seven hours a day. School is approximately six hours a day. The time taken going to and from school, doing homework and activities of daily living must also be included. In addition, those with ME/CFS take longer to do all activities. Thus, it is inevitable that young people with ME/CFS will have difficulty with, or be unable to maintain a full school program. Young people with ME/CFS usually require special educational considerations. Some may only be able to attend school one or two hours a day, while others have to study at home, when they are able.

It is important that the significant physical and mental fatigue of ME/CFS is recognized as a biological reality of the illness and not dismissed as lack of motivation, day dreaming, or school reluctance. Contrary to school reluctance, youth with ME/CFS are usually totally

exhausted after school and spend much of their out-of-school time, including weekends, resting.

## 2. Post-Exertional Malaise and/or Fatigue

The negligible amount of physical or mental activity can now cause severe fatigue, flu-like symptoms, and worsening of other symptoms. A unique characteristic of post-exertional fatigue in ME/CFS is that the fatigue can be delayed by up to three days after the activity. There is a pathologically slow recovery time - usually a day, weeks or more. It is imperative for educators to know that pushing young people with ME/CFS too far or too often beyond their new limits can have serious medical repercussions and cause long-term relapses. Educators are encouraged to assist young people in recognizing what things aggravate their symptoms and how long they can continue activities. A simple aid in determining activity limits that can be done at home is to take their temperature before and after an activity. If their temperature drops after doing an activity, they have done too much. As the severity of symptoms vary from day to day and even hour to hour, what they can do one day does not necessarily mean that they will be able to do the same activity the next day. The activity done one day may deplete their energy for a number of days. A key element in the management of ME/CFS is for young people to learn **self-pacing** by listening to their bodies, learning to recognize early warning signs, stopping before they become exhausted, and incorporating rest periods into their day. After they learn to live within their limits, they can very gradually try to expand their activities at their own pace. It is helpful if educators are alert to early warning signs that indicate these students are reaching their limits, and respect their activity boundaries.

**Exercise:** It is most disturbing that even though post-exertional malaise/fatigue is a hallmark feature and a compulsory criterion of ME/CFS, patients are often prescribed exercise unwisely. It is of utmost importance to realize that research studies have confirmed that people with ME/CFS have different physiological responses to exercise from healthy people. It is easy for lay people to incorrectly assume that children and adolescents with ME/CFS are not motivated or depressed. Healthy people and those who are depressed receive an increased supply of blood and oxygen to the brain during exercise, which invigorates them and makes them feel better afterwards. ME/CFS patients have lost the invigorating effect of exercise. It makes them feel ill; other symptoms worsen, and it can cause a relapse. This abnormal response to exercise can differentiate ME/CFS from depression. While not all ME/CFS patients exhibit all of the following abnormal reactions to exercise, this chart summarizes some of the dysfunctional reactions documented by research studies (12).

RESPONSE TO EXERCISE	HEALTHY PEOPLE	ME/CFS PATIENTS
<b>Sense of well-being</b>	Invigorating Anti-depressant effect	Feel malaise, fatigue and worsening of symptoms (1,13,14)
<b>Resting heart rate</b>	Normal	Elevated(15,16)
<b>Heart rate at maximum workload</b>	Elevated	Reduced heart rate(15,16)
<b>Maximum oxygen uptake</b>	Elevated	Approximately ½ of sedentary controls(15)
<b>Age-predicted</b>	Can achieve it	Can <u>NOT</u> achieve it (15,16)

<b>target heart rate</b>		Potentially dangerous!(16)
<b>Heart functioning</b>	Increased	Sub-optimal level(15,16)
<b>Cerebral blood flow</b>	Increased	Decreased(17,18)
<b>Cerebral oxygen</b>	Increased	Decreased(17)
<b>Body temperature</b>	Increased	Decreased(19)
<b>Respiration</b>	Increased	Breathing irregularities: shortness of breath(19)
<b>Cognitive processing</b>	Normal, or more alert	Impaired(20)
<b>Recovery period</b>	Short	At least 24 hours but it can last days or even weeks(1,13,21)
<b>Oxygen delivery to the muscles</b>	Increased	Impaired(15)
<b>Gait kinematics</b>	Normal	Gait abnormalities(22)

As much care must be taken in prescribing an exercise program as prescribing pharmaceuticals (23). The Expert Consensus Panel recommends that a thorough history and examination, with particular attention to cardiac functioning, be completed in order to determine the patient's total illness burden. Risk factors and pain generators must be identified and addressed. The reality of biological dysfunctions and limitations must be acknowledged. Activity boundaries and fluctuations must be recognized and accommodated. Medical management must be optimized before introducing exercise. As young people with ME/CFS have adverse reactions to exercise and some exercises are potentially dangerous for them, their treating doctor should direct and coordinate all rehabilitative efforts. All rehabilitation personnel must be knowledgeable about ME/CFS. Guidelines for exercise are included in the Consensus Document. It is recommended that young people with ME/CFS be excused from regular physical education classes.

**Youth with ME/CFS must never be pushed to increase their heart rate to age-predicted target heart rates, because this is potentially dangerous (1,16)! Research studies(15,16) suggest that their hearts may be functioning at a suboptimal level and/or they have autonomic disturbances; thus they may not be able to accommodate the cardiac stress.**

### 3. Sleep Dysfunction

Unrefreshed sleep or sleep quantity or rhythm disturbances is a criterion of ME/CFS. When healthy people are tired, a good night's sleep will refresh them. In the acute stage of ME/CFS, people often sleep most of the time. Some people wonder how it is possible for someone to sleep so much and still be exhausted. Research studies(24,25) indicate that ME/CFS patients have sleep dysfunctions and do not get into/or spend sufficient time in the deep stages of sleep, which are needed for their bodies to restore themselves and become rested. Young people may have severe sleep disturbances.

In the chronic stage of the illness, many patients may have trouble staying awake during the day and may have insomnia at night, or have chaotic sleep rhythms. Due to the lack of quality of sleep, they awake feeling as exhausted as when they went to sleep. Although it is not precisely correct, they feel as if their brain did not go to sleep. Just as they feel that their brain did not "turn off" when they went to sleep, they also feel that their brain doesn't "turn on" when they awake. These young people take a long time wake up and get ready

for school. Their responses to verbal communication are likely to be delayed, as if it takes a long time for their brain to process the information. Rest periods should be scheduled into their day to prevent “crashes”. One of the ironies of ME/CFS is that when a patient is totally exhausted and does “crash” insomnia usually increases, causing a further downward spiral.

#### **4. Pain**

Significant pain is a criterion of ME/CFS. There is a dysfunction of the pain processing area of the central nervous system, which can send erratic pain signals to various parts of the body (26). The pain may be difficult for young people to explain as it occurs unexpectedly, often without a known cause, and can quickly migrate from place to place. It usually is perceived as originating in the muscles, but not always. It may be described as burning, aching, stabbing, throbbing, shooting, sharp, etc. There is often widespread generalized pain. There is a lowered pain threshold so pressure that would not be painful to healthy people is painful for these patients. Young people may avoid activities involving body contact or where there is a possibility of being hurt. Pain in the hands may make written work difficult. Many young people who have ME/CFS also meet the criteria of fibromyalgia syndrome (27).

Many young people live with constant low-grade headaches, pain in and behind their eyes, and flare-ups of severe headaches. Migraine headaches are often accompanied a rapid drop in temperature, muscle spasms in the neck and shoulders, shaking, vomiting, diarrhea, and severe weakness. Some people who get frequent migraines lose their ability to focus their eyes and/or get spots in front of their eyes prior to the onset of a migraine headache. Students should be picked up from school by their parents at the first sign of a migraine.

#### **5. Neurological/Cognitive Manifestations**

The brain needs oxygen and glucose in order to function. It has been confirmed by research (17,18) that ME/CFS patients have reduced levels of oxygen and glucose circulating in regions of their brains. It is clear that the many cognitive difficulties exhibited in ME/CFS are very disabling and make it difficult at best or impossible for young people to do their school work and keep up with their classmates. People with ME/CFS often have significant short-term memory deficits, difficulty in concentrating, processing information, sequencing words and numbers, and word retrieval, which are obvious handicaps in school studies (1,28,29). Their slow processing of information makes it difficult or impossible to take notes or follow what is being said when someone speaks quickly. They often have difficulty reading, writing, and doing math. It is important to know that when students are pushed beyond their limits, they not only “crash” physically, but their cognitive abilities also rapidly deteriorate and these effects can last for days or longer (30). Their speech and responses become slower, less coherent, more confused, and they have more difficulty recalling words and information. Students may have trouble focusing their eyes and be unable to read or become dyslexic when they are overly fatigued. Young people may unconsciously develop coping techniques to compensate for their mental fatigue. They may shift their weight and wiggle around to help them stay awake or change the subject for a few minutes in order to give themselves a ‘mental break’. It is important that educators be alert to these signs of cognitive fatigue and make appropriate accommodations.

It is helpful for educators to be aware that young people with ME/CFS often have selective memory processing deficits, even when they have relatively normal overall cognitive functioning. Unlike healthy controls and patients with other kinds of impairments of the central nervous system, young people with ME/CFS have more difficulty recalling information when it is presented with greater semantic structure and contextual clues.

**Overload Phenomena:** Of utmost importance to the learning environment is the fact that many young people with ME/CFS are hypersensitive to noise, bright or fluorescent lights, temperature extremes, odours, and fast-paced or confusing environments. They have difficulty focusing their attention when they have to divide their attention between auditory and visual input (31). They may be unable to exclude background noise,(32) which may be more prominent than the instructions they are trying to hear, in much the same way as being unable to tune a radio to one station. Young people can quickly experience overload phenomena and become disorientated, anxious, and 'crash'. Therefore it is imperative that their learning environment be kept as comfortable and free from distractions as possible. Instructions must be kept simple, clear and concise.

**Motor and Perceptual Disturbances:** People with ME/CFS may experience muscle weakness and twitching. They may have difficulty with muscle coordination or walking a straight line, and may appear clumsy. Difficulty with depth perception and spatial instability commonly occurs. They may bump into walls and be unable to accommodate walking on uneven surfaces. These difficulties become more pronounced with increased fatigue. Young people are sensitive and most anxious to fit in with their peers. Please do not draw attention to their difficulties, but rather be alert to signs of increased fatigue and allow these students to rest as needed.

## 6. Other Symptoms

**a. Autonomic Manifestations:** The autonomic nervous system regulates the action of the glands, the smooth muscles of hollow organs, and the heart. It automatically keeps them functioning within acceptable limits.

Most young people with ME/CFS develop orthostatic intolerance - their bodies are unable to maintain their pulse and blood pressure within normal limits when they are standing in the upright position, particularly standing still (33,34,35). There is a rapid drop in blood pressure when they stand up quickly or it may be delayed by several minutes. Dizziness, wooziness, nausea, and even fainting may occur. Their hearts may begin to race. If they immediately lie down, the symptoms usually go away within a few minutes. Sitting for prolonged periods of time is also difficult. Some students may have heart arrhythmias.

Research studies(18,36) suggest ME/CFS patients have a very significant reduction in circulating blood volume. On average approximately 70% and in a few cases as low as 50% of their blood volume is circulating. In a hospital setting, the Code Blue alarm would be sent out long before a patient lost 30% of their blood. While ME/CFS patients have not actually lost 30% of their blood, it pools in their legs, feet, abdomen and sometimes their hands. This causes them to be very pale, feel weak and often light-headed due to the reduced supply of oxygen and blood to their brains. When young people with ME/CFS stand, they often fidget, shift their weight from foot to foot, put a knee on a chair, put their head down, hold their head, slouch, lean against a wall, or remain at their desk until the class begins to move. These are all signs of attempts to compensate for the rapid drop in blood pressure experienced in orthostatic intolerance. It is important that educators are alert to these signs; and it is imperative that these students are not required to stand still, even for short periods of time. Placing a couple of books under their feet while sitting may help reduce the amount of blood pooling in their legs.

Youth with ME/CFS may need more frequent bathroom breaks because of increased urinary frequency and/or bowel dysfunction.

- b. Neuroendocrine Manifestations:** Most people with ME/CFS have impaired thermostatic stability. Their body temperature is usually lower than normal and may fluctuate erratically. They may have recurrent feelings of feverishness and low-grade fever. When over-fatigued, patients often suddenly feel very cold. Young people are often intolerant to extremes of heat and cold and may not be able to tolerate being outside when it is either very hot or cold.

A marked change in weight, either weight gain or loss, often occurs, but this may take place over an extended period of time. Young people may experience more severe appetite disturbance than adults.

Children or adolescents may appear depressed because their personality may become “flattened”. Who does feel cheerful and peppy when they have a severe case of the flu or are so exhausted that all they can think about is lying down? As with any chronic illness, some of these young people experience reactive depression as a result of their symptoms and impairments. A smile and a kind word are always greatly appreciated.

- c. Immune Manifestations:** The immune system may be on overdrive (up-regulated) or is exhausted and has “crashed”. Patients often have recurrent sore throats, flu-like symptoms, and tender lymph nodes, especially in their neck and/or arm pits.

Many young people with ME/CFS develop new sensitivities to food, medications and/or chemicals. These young people should not be exposed to substances that may provoke reactions. If educators are aware of upcoming renovations in the school, such as painting or installation of carpet, they should give parents advance notification so that these students can be kept home on that day. This simple precaution may prevent a relapse or an emergency visit to the hospital.

**Immunization:** The decision whether or not a ME/CFS patient should be vaccinated must remain with the treating physician and the patient’s parents. There is controversy regarding the advisability of immunization for these patients because it may worsen their ME/CFS condition. Research has confirmed a frequent breakdown of one of the body’s antiviral defense pathways. If the physician and parents do decide to immunize the patient, general recommendations are that the injections be administered by the treating physician and the dose be divided into three or four doses each given a full month apart to assure there are no delayed reactions. Thus, the school should give parents of ME/CFS students advance notice of upcoming immunization programs and the treating physician should give written notification to the school if the young person should not have vaccinations or if it will be done under his/her care.

## Summary

The symptoms of ME/CFS may progress more slowly in young children than in teenagers and adults. Young people with ME/CFS often have numerous prominent symptoms but the order of severity often differs more dramatically from day to day than in adults. It can be particularly frustrating and difficult to manage symptoms that fluctuate from day to day and from hour to hour, even when patients are able to do limited activities. It is important that educators are aware that the significant fatigue of ME/CFS has different characteristics from normal fatigue

and that if these students exceed their activity limitation, they can have serious medical repercussions.

## **Educational Implications**

Young people with ME/CFS face many physical, mental, educational, social and emotional challenges, which also affect their families, friends and school studies. Students require special educational considerations. Some children and adolescents may only be able to attend school a few hours a day, while others may be homebound. The biggest cause for long-term absence from school is ME/CFS (37,38). In a British study of long-term school absence of children in 1098 schools, a shocking 51% of students absent suffered from ME/CFS (39). It is important that a wide range of educational opportunities be made available for these young people. Overwhelming fatigue, cognitive dysfunction and the potential for relapse are prime concerns.

### **Goals and Guidelines for Educational Planning**

*(Adapted from the ME/CFS Consensus Document [1])*

#### **Goals**

The Expert Consensus Panel emphasizes the following top priorities in any rehabilitative efforts:

##### **1. The support and well-being of the patient**

These young people have a poorly understood chronic illness and are unable to participate in the normal activities of childhood and adolescence. Educators have an opportunity to be supportive and lessen the state of uncertainty and confusion of these young people. Educators can also influence the opinion of these students' peers regarding the reality of the illness.

##### **2. Patient empowerment**

An integral part of empowering youth with ME/CFS is to validate and respect their knowledge of their body and experiences. It is essential for the physiological and psychological well-being of patients that they are able to maintain autonomy over the complexity and pacing of activities. Educators can assist these young people in setting personal and emotional boundaries.

##### **3. Optimizing functional ability**

The aim is for youth to achieve activity boundaries in which they can be as active as possible without aggravating their symptoms and then gradually extending their activity boundaries at their **own pace, as they are able**.

#### **Guidelines**

##### **1. The treating physician is responsible for the patient's care and should oversee all rehabilitative efforts.**

It is helpful if the treating physician provides a letter to the educators outlining the patient's medical condition and limitations. Open communication and feedback is essential so that strategies can be assessed and adjusted.

##### **2. Educators should meet with the student and parents**

As soon as a student has been diagnosed with ME/CFS and at the beginning of each school term, the educator should meet with the parents and student. It is very challenging for parents to care for a chronically ill child, particularly when the child has a poorly understood illness. Collaboration among educators, parents and the student is advised. Parents should

be encouraged to provide written information about their child's difficulties to be given to all of their child's teachers.

### **3. The biological pathology of ME/CFS must be respected and reflected in educational accommodations.**

- All the patient's symptoms must be taken into consideration in order to address his/her total illness burden. The complex and varied dysfunctions and their interactions must be taken into account in determining what accommodations need to be made.
- ME/CFS is classified as a neurological illness. As a result of brain dysfunction, patients will have cognitive difficulties. However, the cognitive difficulties may vary both in kind and severity from individual to individual.
- The patient's physical limitations, emotional symptoms, and activity boundaries are biological realities of ME/CFS.
- The patient's activity boundaries fluctuate from day to day, from hour to hour, and s/he lacks stamina. When a student is having a "bad day", it is unrealistic to expect him/her to do math or other subjects that require concentration. Pushing the student beyond her/his limits will worsen the overall condition. A great deal of flexibility is required in accommodating the marked fluctuations in physical stamina and cognitive difficulties.
- Patience is required. It is essential that the student does not exceed limitations. Severe relapses can be triggered by transgressing the youth's endurance and/or activity boundaries too often or too deeply. A young person with ME/CFS should be excused from regular physical education classes.
- Energy conservation is of prime importance. The student's limited energy for the day must be used wisely in order to enhance the student's ability to participate in school activities. Even if a student can walk, the use of a wheelchair may conserve his/her energy for other activities, but the emotional impact of using the wheelchair must also be considered. Self-pacing, resting before and after any form of energy exertion, will help to increase the number of activities in which the student can participate.
- It is imperative that educational programs do not exacerbate the patient's symptoms.

### **4. Educational accommodations must be individualized**

The severity and hierarchy of symptoms, aggravators, and activity limitations will vary with each youth who has ME/CFS. It is important that educators are sensitive to and accommodate the limited energy levels of the young person when planning her/his program.

- Each student will require different accommodations and approaches according to different and unpredictable energy levels and activity limitations.
- Sometimes a young person is unaware of early warning signs or ignores them because s/he wants to fit in with his/her peers. An alert educator will become aware of symptoms such as extreme pallor, general uneasiness, slowing and deterioration of speech and work, anxiety, and emotional distress as signs that the student is entering an exhaustion phase. An educator can empower the student by assisting him/her in recognizing and monitoring early warning signs and excessive fatigue, and preventing crashes.
- Begin the program at a level that will ensure the student's success. If a student cannot attend school a full day, it is better that s/he begins with one to two hours and then increase the time by one hour if and when the student feels s/he can do more. It is much better for a student to attend school for a short interval every day than to attend for longer intervals and have many absentees. After resting during the summer holidays, the student may feel that s/he can attend school for longer periods. This strategy is not advised because it often results in the student "crashing". Being able to

maintain social contact with peers is beneficial, but it is always secondary to the patient's health.

- The patient must have autonomy over the pacing of activities. Pacing must be very flexible and accommodate times when little can be achieved.
- ME/CFS students will require extra time to complete assignments and exams.
- The environment should be a comfortable temperature, and as free from distractions and confusion as possible. The student's body may not be able to adequately regulate its temperature so the student may need to wear extra or lighter clothing.
- Avoid sensory and information overload and excessive speed. The student's difficulties in concentrating, retrieving words and information, and multi-tasking rapidly further deteriorate with pressure for excessive speed. Forgetfulness is very common and not meant to annoy.
- Keep directions simple, clear and concise.
- ME/CFS students may need to eat or drink in class. If they do not eat when their body requires nourishment they can very suddenly become weak, nauseated, disoriented, and/or faint.
- It is helpful for schools to issue ME/CFS students two sets of school books, one for school and one for use at home, so that they do not have to carry the books back and forth.

## 5. Student participation

The student is aware of his/her own body and how s/he feels. Educators can empower the student through respect. When the student is involved in establishing priorities and strategy decisions, s/he will be more motivated to succeed and misunderstandings will be minimized.

- Involve the student in planning flexible and realistic goals.
- **The patient must have autonomy over the complexity and pacing of activities.** One of the most important features of managing ME/CFS is that the patient learns to **self-pace** activities. When the patient becomes aware of warning signs and learns to pace his/her activities according to her/his fluctuating abilities/limitations, s/he can then very gradually explore ways of increasing activities as his/her ability allows. Self-pacing is the best way to ensure continued commitment and success.
- Rest intervals should be incorporated into the school day as needed.
- Involve the student in developing strategies in advance for times when s/he is feeling overly fatigued or having flare-ups.
- The teacher and student can develop prearranged signs or the teacher can give the student a "pass card" to show so that simple accommodations that have been agreed upon, such as taking a rest, wearing sunglasses, eating a snack to regain strength, not standing in line, or being excused to go to the bathroom can be made without discussion or disruption of the class. (See note at end of chapter.)

While the principles of educational planning are briefly mentioned, many educational accommodations are more complex and are discussed in detail in later chapters.

## Combining School and Home Tutoring

Often attending school or being tutored at home are considered an either/or decision. Some young people may be able to attend for one or two subjects and have home tutoring for the remaining subjects. Those who are too ill to attend school on a regular basis may benefit from visiting school for social contact but the patient's health is always the top priority.

## **Education for Homebound Youth**

Programs for children and youth who are homebound due to temporary or chronic illnesses need to be developed as special needs placements. Some patients may take a course by correspondence while others may take a main course and a light course so that they can do the main course on better days and the light one on days where their energy is more limited. Internet based instructions for the various subjects and grades would be of great assistance to all homebound young people. It would be particularly helpful for such programs to include an opportunity whereby students can email questions to educators. Severely afflicted children may be too ill to use a computer so other arrangements need to be made for such cases. Home tutoring, correspondence courses and taped lessons may be of assistance. If a school has internet access, students attending school may be able to send short messages to a young person who is homebound and isolated.

Living with ME/CFS definitely is a challenge for children and youth. As there are numerous activities that these young people cannot do, they should be encouraged to develop interests in things they can do. Some may be able to read for short periods or write poems or short stories. Others may not be able to write but may be able to water paint for a few minutes at a time. Some may enjoy listening to taped stories or soothing music.

The National ME/FM Action Network website <http://www.mefmaction.net> includes a Youth Site where parents and educators can obtain further information. If you have a tip that may help others assist young people with ME/CFS or educators, we would like to hear from you. We also post poems and short stories written by young people with ME/CFS. Submission guidelines and contact information are on our Youth Site. Students may find it rewarding to have their poems posted on a national website. Many people are most interested in reading them.

## **Young people have the right to access education according to their circumstances:**

**These children have got to be taken as seriously as with any other neurological disease. They will not stabilize if they rush back to school. We have to give them our total support.** - Dr. Elizabeth Dowsett, Honorary Consultant Microbiologist to the South Essex Health Trust, the ME/CFS clinic at St. Andrew Hospital, UK, and Honorary International Medical Advisor to the National ME/FM Action Network.

**The purpose of education is to educate, not just to put children into schools. Social isolation can be addressed separately.** - Jane Colby, former Head-teacher, member of the National ME Task Force Focus Group on Children, UK; Consultant for the Education of Children with ME; and author of *ME – The New Plague*

**When parents, educators, and meaningful others remain patient, understanding, and supportive, they can bring a sense of hope to these young people. Listen to them, target goals to assure success, and assist them in acquiring the education they dearly desire. A caring educator has the opportunity and privilege of being able to touch the hearts and souls of these young people and make a difference in their delicate lives!**

**Note:** Following a report by the Chief Medical Officer's Working Group, which stated that "Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms", the Department of Health in the United Kingdom has endorsed the

use of a “pass card” to protect the health of children with ME/CFS while they are in school (37). The “pass card” has the child’s photograph, is signed by the principal, and states that the child has permission to use the school’s disabled facilities or obtain other assistance. Accommodations are agreed upon in advance. The child simply needs to show the teacher the card as required. The National ME/FM Action Network would like to spearhead a drive to do the same in Canada. If you are able to assist us or have any suggestions in furthering this cause please contact Marjorie van de Sande at [mvandes@shaw.ca](mailto:mvandes@shaw.ca)

*Most medical information in this chapter is from the ME/CFS Expert Consensus Document. This informative document includes the clinical definition, discussion of the symptoms, diagnostic and treatment protocols, and a research overview. Guidelines for self-management strategies, exercise, and practical appendices are also included. The document may be viewed on the National ME/FM Action Network website, and instructions for ordering the journal are provided.*  
<http://www.mefmaction.net>

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## Chapter 2

# Understanding Fibromyalgia Syndrome (FMS) in Young People

By

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## Introduction

This chapter will give educators a better understanding of Fibromyalgia Syndrome (FMS). The Clinical Diagnostic Criteria for FMS are included in order for educators to be aware of the many symptoms, in addition to pain, that FMS potentially encompasses. It is hoped that this understanding will enhance the educator's ability to accommodate young people with FMS in the school setting.

### What is FMS?

**Fibro** refers to fibrous tissue – ligaments and tendons, **myo** refers to muscle, and **algia** refers to pain. Fibromyalgia involves widespread pain of the muscles, ligaments, and tendons. A syndrome is a set of medical signs and symptoms that are seen together. Fibromyalgia is a soft-tissue pain syndrome that is classified as non-articular rheumatism in the World Health Organization's International Classification of Diseases. As in other medical conditions, the severity of FMS varies from mild to severe and it can be debilitating.

### What Causes FMS?

A physical trauma, particularly a whiplash or spinal injury, can trigger FMS in many patients. There appears to be a genetic factor involved in some patients. In other patients, FMS comes on gradually with no known cause.

### How Prevalent is FMS?

Studies estimate that between 2% and 10% of the general population have FMS(1,2,3). In a prevalence study of randomly selected school children, 6.2% met the criteria for FMS (4). It is two to five times more common than rheumatoid arthritis.

### Who Gets FMS?

FMS affects all age groups, including children, all racial/ethnic groups, and all socioeconomic strata.

As in many painful conditions, such as arthritis, there is a higher prevalence of FMS in females. Although all the mechanisms are not fully understood, some gender differences are known (5). Females generally have a more flexible and delicate skeleton, longer necks, and thinner, less massive muscles than males. Thus, females are more prone to neck and spinal injuries. Females generally have a narrower spinal canal than males. A study found that those

(particularly females) who had persistent whiplash injury symptoms had a significantly narrower cervical (neck) spinal canal (6). As the spinal canals of children are narrower than adults, they may be more vulnerable to such injuries. Studies have found that females have a lower pain threshold (the point when a stimulus is perceived as painful)(1) and a greater increase in pain over time than males (7). Females produce more of some brain chemicals that increase pain signals and less of some other brain chemicals that decrease pain signals. A remarkable finding was that when endogenous (inside the central nervous system) tryptophan was depleted, there was only a 7-fold drop in synthesis of serotonin (a chemical that decreases pain sensation) in males but there was a dramatic **42-fold drop** in the synthesis of serotonin in females (8). This finding would certainly be an important factor in females having lower pain thresholds. Both the direction and magnitude of the brain's response to pain differs in males and females with females being more sensitive to pain (9).

### **What is the Natural Course of FMS?**

An eight year study indicated that once FMS is established, symptoms generally did not improve and functional disability slightly worsened (10). In another study, all patients still had FMS fifteen years later (11).

### **What is the Difference Between FMS and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)?**

There is an overlap of symptoms between FMS and ME/CFS and many think they may be variants of a similar disease process. FMS is often triggered by a physical injury with pain and dysfunction of the muscles, ligaments and tendons being more prominent. ME/CFS is often triggered by a viral infection and there is more pronounced fatigue, post-exertional malaise and dysfunction of cognitive abilities and other body systems.

## **Clinical Definition of Fibromyalgia Syndrome (FMS)**

The International Expert Consensus Panel, selected by Health Canada, consisted of thirteen doctors who were actively diagnosing/treating FMS and/or were researchers in this illness. Collectively, they had diagnosed and/or treated more than 20,000 FMS patients. They agreed that the 1990 American College of Rheumatology criteria were well established, accepted worldwide, and had good sensitivity and specificity for research. The Clinical Definition encompasses the potential spectrum of the symptomatic expressions of FMS. There was 100% consensus among panel members on the final document.

### **Canadian Clinical Working Case Definition of FMS (12)**

*The two compulsory pain criteria ( adopted from the American College of Rheumatology 1990 Criteria [13]) are merged with Additional Clinical Symptoms & Signs to expand the classification of FMS into a Clinical Working Case Definition of FMS.*

- 1. Compulsory HISTORY of widespread pain.** Pain is considered widespread when all of the following are present for at least three months:
  - Pain in both sides of the body
  - pain above and below the waist (including low back pain)
  - axial skeletal pain (cervical spine, anterior chest, thoracic spine or low back).  
Shoulder and buttock involvement counts for either side of the body. "Low back" is lower segment.

**2. Compulsory PAIN on PALPATION at 11 or more of the 18 defined tender point sites.**

**3. Additional Clinical Symptoms & Signs.** In addition to the compulsory pain and tenderness required for research classification of FMS, many additional clinical symptoms and signs can contribute importantly to the patients' burden of illness. Some of these features are present in most FMS patients by the time they seek medical attention. On the other hand, it is uncommon for any individual FMS patient to have all of the associated symptoms or signs. As a result, the clinical presentation of FMS may vary somewhat, and the patterns of involvement may eventually lead to the recognition of FMS clinical subgroups. These additional clinical symptoms and signs are not required for the research classification of FMS but they are still clinically important. For these reasons, the following clinical symptoms and signs are itemized and described in an attempt to expand the compulsory pain criteria into a proposed Clinical Case Definition of FMS.

- a) Neurological Manifestations:** Neurological difficulties are often present such as hypertonic and hypotonic muscles; musculoskeletal asymmetry and dysfunction involving muscles, ligaments and joints; atypical patterns of numbness and tingling; abnormal muscle twitch response, muscle cramps, muscle weakness and fasciculations. Headaches, temporomandibular joint disorder, generalized weakness, perceptual disturbances, spatial instability, and sensory overload phenomena often occur.
- b) Neurocognitive Manifestations:** Some neurocognitive difficulties usually are present. These include impaired concentration and short-term memory consolidation, impaired speed of performance, inability to multi-task, and/or cognitive overload.
- c) Fatigue:** There is persistent and reactive fatigue accompanied by reduced physical and mental stamina, which often interferes with the patient's ability to exercise.
- d) Sleep Dysfunction:** The patient experiences unrefreshing sleep. This is usually accompanied by sleep disturbances including insomnia, frequent nocturnal awakening, nocturnal myoclonus, and/or restless leg syndrome.
- e) Autonomic and/or Neuroendocrine Manifestations:** These manifestations include cardiac arrhythmias, neurally mediated hypotension, vertigo, vasomotor instability, sicca syndrome, temperature instability, heat/cold intolerance, respiratory disturbances, intestinal and bladder motility disturbances with or without irritable bowel or bladder dysfunction, dysmenorrhea, loss of adaptability and tolerance for stress, emotional flattening, lability, and/or reactive depression.
- f) Stiffness:** Generalized or even regional stiffness that is most severe upon awakening and typically lasts for hours commonly occurs. It can return during periods of inactivity during the day.

Jain AK, and Carruthers BM, co-editors. van de Sande MI, Barron SR, Donaldson CCS, Dunne JV, Gingrich E., Heffez DS, Leung F Y-K, Malone DG, Romano TJ, Russell IJ, Saul D, Seibel DG. **FIBROMYALGIA SYNDROME: Canadian Clinical Working Case Definition, Diagnostic and Treatment Protocols. A Consensus Document.** *Journal of Musculoskeletal Pain* 11(4):3-107, 2003. Published simultaneously in: **The Fibromyalgia Syndrome: A Clinical Case Definition for Practitioners.** I Jon Russell, Editor. *Haworth Medical Press*, pg. 3-107, 2004. © Copyright 2004 Haworth Medical Press Inc., 10 Alice Street, Binghamton, NY 13904-1580, **reprinted with permission.** (The FMS Consensus Document may be viewed on the website of the National ME/FM Action Network at <http://www.mefmaction.net>. Instructions for ordering this informative book are also on our website.)

## Symptoms and Signs of FMS

As indicated in the clinical definition, in addition to the two compulsory pain criteria, patients with FMS are expected to exhibit many of the additional symptoms. However, it is unlikely that a patient will exhibit all the additional symptoms and they may vary over time in different combinations. The severity and hierarchy of severity of symptoms tend to vary more dramatically from day to day in young people.

### 1. Pain

Do you recall the fairy tale where the princess could feel a pea under her mattress? FMS patients are extremely sensitive to pain and a fold in their night-clothes may cause enough pain to wake them up. How long can you hold a muscle in a flexed state before it becomes tired – 5, 10, 15 minutes? Many FMS patients are living with muscles that are permanently contracted and relentlessly pulling on their joints. Muscles that are shortened by contractures constantly ache, are dysfunctional, and are chronically fatigued.

Although the pain may begin as regional pain from an injury, instead of the pain going away, over the course of months it becomes widespread and increases in severity. Thus, there is a delay in the onset of FMS. Many research studies suggest that there are abnormalities in the interaction between the peripheral nervous system and the central nervous system in processing pain (12). FMS patients have higher levels of some chemicals that increase pain signals to the brain and lower than normal levels of some other chemicals that decrease pain signals. These unusual levels result in miscommunication between the brain and the body. Unopposed pain signals are being sent from the body to the brain and from the brain to the body.

**Types of Pain:** The sensation of pain varies in type, severity and its location often quickly shifts. Young people may describe their pain as burning, tingling, deep, shooting, sharp, stabbing – like a knife stuck in them, deep aching, feeling bruised all over, like someone used them as a punching bag, or any combination of these.

**Understanding FMS Pain:** It is easy to understand that a bruise or cut can cause pain. However, it is often difficult for those who are not well informed about FMS to believe that a young person could possibly experience so many types of pain, particularly when they say they are always in pain, the pain migrates to different parts of the body, and there is no visible evidence of injury. For example, if a child complained of pain in one leg and was favouring that leg when s/he was walking and then a few minutes later you observed that s/he was favouring the other leg, what would be your reaction? Would you smile to yourself and think that the child was faking it and couldn't even remember which leg s/he said was hurting? In actuality, when someone with FMS walks favouring one leg it puts more stress on the joints and muscles in the other leg and those muscles may spasm and/or send pain signals to the brain causing the pain to shift to the other leg.

It is most important for educators of FMS students to be cognizant of the fact that these young people have a dysfunction in the areas of the central nervous system that process pain resulting in inappropriate pain signals being sent to different parts of the body. Not only are these young people abnormally sensitive to pain, but after a painful stimulus the pain lasts for a much longer period than normal. Most readers have experienced a time when they were out walking and discovered that their shoes didn't fit properly and were causing blisters. How eager they were to get home quickly and take their shoes off their

sore feet! How would they react to someone telling them to forget their pain and get in the gym and run? Similarly, young people who are in pain have a low endurance and are apt to be reluctant to participate in activities which involve physical contact and/or increases their pain. If their hands hurt, they may have difficulty writing and may not want to hold hands with other students.

Young people with FMS often fidget and squirm in their desks either because they are trying to find a different position that will relieve their pain or they are fatigued and are trying to stay awake. FMS students usually are unable to sit for extended periods of time because staying in one position increases their pain and may cause muscle spasm. They need to be accommodated by allowing them to stand up and walk around for a few minutes as required. On the other hand, some FMS patients can only stand for a very short time, particularly in one spot, and need to avoid doing so.

Because young people with FMS have extremely low pain thresholds and often have seemingly bizarre pain patterns, they may be labelled as whiners. It is most unfortunate that children who are suffering often are not taken seriously, or their pain is dismissed as "growing pains". Growing should not cause this much physical pain. Young children are eager to please and gain respect. When adults do not understand the depth of pain these children feel, there is a risk that they become withdrawn for fear of being ridiculed, and may not receive appropriate medical treatment in a timely fashion. **It is essential that educators know that the pain these young people experience is real, there is a physiological reason for their pain, and it can be severe and exhausting.**

**Exercise:** As exercise is often prescribed to young people with FMS, it warrants special attention. Out of 1,808 multi-disciplinary studies that were systematically reviewed,(14) only seven met the criteria for methodology, and of these two included exercise for FMS patients. The results were disappointing. Another review(15) of 26 studies of exercise intervention programs for FMS also gave disappointing results and attrition rates ran as high as over 60%, while some studies failed to report attrition rates. There is no reliable evidence that explains why exercise will reduce pain (16).

As much care must be taken in prescribing exercise programs as in prescribing pharmaceuticals (17). The Expert Consensus Panel recommends that a thorough history and examination be completed in order to determine the patient's total illness burden. Risk factors and pain generators, such as prior injuries, hypermobile or restricted joints, taut muscles, balance problems, and risk for adverse cardiac reactions must be identified and addressed. There are no exercises that can strengthen or heal lax or injured ligaments. The tighter the muscles, the easier they are activated – even when they shouldn't be. The opposing muscles appear weak, but are dysfunctional. The longer the muscles have been contracted, the more dysfunctional they are. The reality of biological dysfunctions and limitations must be acknowledged and accommodated. Medical management must be optimized before introducing exercise. The patient's treating doctor should direct and coordinate all rehabilitative efforts and all rehabilitation personnel must be knowledgeable about FMS. Exercises must be individualized and specific to the physical pathology of FMS. Young people with FMS, particularly if they also have ME/CFS, must never be pushed to increase their heart rate to average acceleration. This is potentially dangerous because their hearts may be functioning at a suboptimal level! It is essential to warm and stretch tight muscles and these muscles must be released before trying to strengthen 'weak' dysfunctional muscles. Taut muscles are pain generators. When a healthy person becomes stiff, exercise alleviates the stiffness. However, a person with FMS often stiffens with

exercise because the muscles tighten to prevent further injury. It is of prime importance that the exercise does not worsen the patient's condition. There is an informative section on guidelines for exercise for FMS patients in the Consensus Document.

## 2. Tender Points

There are specific, distinctive points on the body called "tender points". When they are touched with a force that is not painful to healthy people, they produce pain in patients with FMS. It is incongruent that they are called "tender points" because it is considered a negative finding if these point present as tender: They must be painful. Many of the tender points are located where ligaments, tendons, or muscles attach to bones.

Some lay people rather dismissingly think that if you poke a person with FMS in some places it hurts, and that's all FMS is. However, the painful tender points are simply a diagnostic tool. Just as a painful left arm can indicate malfunction of the heart, painful tender points indicate that there is dysfunction in the central nervous system related to pain processing.

## 3. Additional Symptoms

a. **Neurological Manifestations:** People with FMS usually have a number of neurological manifestations.

- **Ligaments, tendons and muscles are usually involved in producing pain in FMS:** Although the pain is most often felt in the muscles and joints, ligaments and tendons are also sensitive to pain. When ligaments are overstretched, they are easily injured and are difficult to heal because they have a limited blood supply, particularly where they attach to the bone. Lax or injured ligaments do not hold the joints in place properly so there is abnormal joint movement. When there is abnormal movement of a joint, muscles around the joint tend to react by contracting in order to help stabilize the joint and prevent further damage. However, muscles cannot do the job of ligaments so the contracted muscles constantly stress the joints, including vertebrae, and sometimes pull them out of alignment. This stress puts even more stress on the muscles, which in turn puts more stress on the joints, and so the vicious circle continues. The lax/injured ligaments may cause the joints to be hypermobile, or restricted due to muscle contraction. Over an extended time period, often years, the posture of FMS patients may become abnormal and their body may become lopsided. Due to muscle contraction, typically their head is too far forward, and their shoulders are too high, too far forward and become rounded. One leg often becomes functionally shorter (the legs measure the same length but one is shorter due to the pelvis being tilted and/or rotated).

It is important that educators know that failure of the joints and other supportive structures causes pain and structural fatigue, which inhibits the length of time a person can stand (12). Those whose posture has become abnormal are often told to stand up straight and put their shoulders back. Although these young people would love to have good posture, they simply can't achieve it. Young people are sensitive so it is important not to draw attention to these abnormalities.

- **Other muscle abnormalities:** As mentioned, many muscles may be contracted and taut. When one muscle is contracted, its opposing muscle accommodates by remaining lax and it is dysfunctional. Youth with FMS are prone to muscle cramps, twitching, and weakness. They may also have generalized weakness.
- **Numbness and tingling** are common, particularly in the legs, feet, arms and hands.

- **Headaches**, including migraines, are common and usually are accompanied by spasms in the neck and shoulder muscles. Some young people may get double vision, see spots in front of their eyes, or have trouble focusing their eyes shortly before the onset of a migraine. If an educator has a student prone to migraines, it is helpful to be alert to these pre-onset symptoms and the student should be picked up by his/her parent as soon as possible.
- **Temporomandibular joint disorder (TMJ)**: In FMS patients, TMJ is usually caused by chronic contraction of the muscles that are involved in jaw movement. Some students with TMJ may find it too painful, or be unable to open their mouths wide enough to sing. In these cases, they should be excused from singing or at least not be expected to open their mouths wide.
- **Perceptual disturbances and spatial instability**: Young people may periodically have difficulty focusing their vision, which may be brought on by exhaustion or precede a migraine. It can be confusing to the educator when FMS students say that they can't read the writing on the blackboard or in a book when they could shortly before and may be able to again an hour or so later. The problem is not that they suddenly become shortsighted or longsighted but rather the muscles that focus their eyes are not working properly. In addition, eye fatigue may be increased by straining to try to focus their eyes and many FMS patients have abnormally dry eyes. If students are prone to eye fatigue, consider suggesting the following quick exercise to be done periodically as a preventative measure: "**Palming**"(12) is a simple technique that temporarily reduces eye strain. Simply close your eyes and cup your hands over your eyes putting gentle pressure on the top of the cheek bones from the base of both palms. Hold for one minute and then blink several times.

Young people may not be able to hear or understand instructions because background noise may be more pronounced than the instructions. Their brains may be unable to give the appropriate relevance to auditory input in much the same way as not being able to tune a radio to one station. They may experience ringing in their ears, which usually comes and goes rather than being constant. At such times, children find it more difficult to hear and may become frustrated.

Some young people may have difficulty timing and sequencing their actions, walking in a straight line, and they may bump into things and appear clumsy. They may have difficulty with depth perception and walking on uneven surfaces. It is best not to draw attention to these abnormalities and to be aware that when these difficulties become more pronounced, it is a sign that the student is over-fatigued and needs to rest.

- **Overload phenomena**: Young people may be hypersensitive to a variety of sensory inputs such as bright or fluorescent lights, sound, noise, speed, odours, or any combination of these. It is important that the learning environment be as free from distractions as possible. Cold intolerance is very common and some may have heat intolerance. Cold temperatures can cause these young people's muscles to spasm so they may not be able to go outside on cold days.
- b. **Neurocognitive Dysfunction**: The cognitive difficulties of young people with FMS are generally less severe than those who suffer with ME/CFS but never-the-less they can be debilitating. The symptoms are often more associated with pain and cognitive fatigue than fixed impairments. The cognitive fatigue experience by FMS patients is commonly referred to as "fibro fog", and is characterized by confusion, difficulty

consolidating short-term memories, forgetfulness, and difficulty with word and information retrieval.

A notable feature is that their cognitive functions and responses become markedly slower. It is not that they are unable to understand the concepts when they are feeling better, but rather that their brains process information slowly and it takes them a long time to complete a project or assignment. It may be difficult for them to understand what is being said when someone speaks quickly. They may have difficulty with reading, writing and math, and taking notes may be very challenging. Their responses become even more markedly slower as their fatigue increases, which is a sign that they need to rest.

Young people with FMS quickly experience cognitive overload when they receive information at a faster rate than they can process. They will have difficulty making decisions, multi-tasking, and may “crash” (become temporarily immobilized by fatigue).

- c. **Fatigue:** Chronic pain and stiffness are exhausting. The fatigue and stiffness experienced by young people with FMS are generally worse in the morning but can come unexpectedly from activities that would not tire a healthy person. This reactive fatigue can be delayed by a day or more and is almost always accompanied by increased pain and worsening of other symptoms. Recovery time is longer than normal.

Structural fatigue, due to abnormalities in the joints or discs, results in the body being unable to support itself for sustained periods. This type of fatigue is common in FMS and is relieved by sitting or lying down. Muscular fatigue is prominent in FMS and is associated with muscle dysfunction. It is triggered by movement and relieved by stopping the movement but recovery may take a long time. Most FMS patients have arousal fatigue as a result of poor sleep quality and quantity. This poor sleep quality usually plays an important role in their cognitive fatigue. Oxygenation fatigue may be experienced. In some young people with FMS, the muscles around the chest and between the ribs are contracted so tightly and are so painful that the motion of the chest wall is markedly restricted, causing their breathing to be very shallow. This shallow breathing decreases the body's ability to deliver enough oxygen to the tissues and brain. It is helpful for educators to be aware of the types of fatigue young people with FMS experience and accommodate their fatigue appropriately.

- d. **Sleep Dysfunction:** Young people with FMS usually have difficulty falling asleep often because they cannot stay in one position long enough as a result of their pain. Many wake up frequently and have trouble getting back to sleep. Most patients with FMS do not spend enough time in the deep stages of sleep where the body restores itself and becomes rested (18). This poor sleep quality is a contributing factor to their widespread, diffuse pain and cognitive difficulties. A research study(19) had demonstrated that insufficient deep sleep causes painful tender points upon palpation, suggesting that the lack of deep sleep plays an important role in FMS. Patients wake up feeling utterly exhausted. It is very hard for them to get going in the morning. Some of these young people also have other sleep dysfunctions, such as restless leg syndrome. How often have you heard someone complaining that they are so exhausted because they hardly slept the night before? Children and youth with FMS experience a lack of sleep quality and usually sleep quantity night after night, week

after week, month after month, and year after year. Please allow them to take short rests as needed.

- e. **Autonomic and/or Neuroendocrine Dysfunctions:** Many young people with FMS experience some dysfunctions of the autonomic nervous system. It is very common for them to become dizzy, lightheaded, and lose their balance when they extend their neck, quickly rotate it, or get up quickly. These symptoms are usually relieved quickly by lying down and being still. Some FMS patients have a lower than normal body temperature, and may experience bizarre patterns of hot and cold sensations. For example, one side of their body may feel cold and the other feel hot. Cold temperatures often cause muscle spasm and pain. At other times, they may sweat excessively after limited physical activity. Some have swelling of their feet and hands while others may have dry eyes and mouth. If an FMS student does have a dry mouth, they may need to take sips of water or juice periodically. Others may have to be excused to go to the bathroom more often as a result of increased urinary frequency and/or bowel dysfunction. Teenaged girls often have very painful menstrual periods.

Young people with FMS usually have less tolerance for stress and easily become overwhelmed. It is helpful if they are given one task at a time.

- f. **Stiffness:** Nearly all young people with FMS are stiff when they wake up and it usually lasts for hours. Stiffness can return at other times during the day, generally when the young person has been inactive for some period, such as sitting in their desk too long. Exposure to drafts or cold weather can also trigger stiffness.

### Summary

Young people with FMS have a dysfunction in the areas of the central nervous system that process pain. In addition to the generalized, widespread pain, they experience inappropriate and sometime rather bizarre pain sensations. The pain can quickly migrate from one place to another. Although many of their pain sensations fluctuate, contracted muscles and abnormal joint movement can cause constant pain and are easily aggravated. Their pain can be severe and exhausting.

## Educational Implications

Young people with FMS face many physical, mental, educational, social, and emotional challenges, which also affect their families and friends. The pain and the numerous types of fatigue experience adversely affect their cognitive abilities and educational studies. Because of their slowed cognitive processing and fatigue, it is difficult for them to complete their school work and keep up with their classmates. They easily become confused and overwhelmed. Many FMS students require special educational considerations.

### Goals and Guidelines for Educational Planning

*(Adapted from the FMS Consensus Document [12])*

*The goals and guidelines for educational planning for FMS students are basically the same as for ME/CFS students. However, with FMS patients there is greater emphasis on accommodating pain symptoms and with ME/CFS there is greater emphasis on fatigue, post-exertional malaise, and cognitive symptoms. Many of these patients have overlapping symptoms and indeed some meet the criteria for both illnesses. For those educators who are specifically looking for information to assist them in accommodating FMS patients, the goals and guidelines are basically repeated from chapter 1.*

## Goals

The Expert Consensus Panel emphasizes the following top priorities in any rehabilitative efforts:

### 1. The support and well-being of the patient

Because FMS is a poorly understood chronic illness, educators can lessen the confusion and uncertainty often experienced by these patients by being supportive and influencing the opinion of these students' peers regarding the illness.

### 2. Patient empowerment

It is essential for the patient's physiological and psychological health that s/he is able to maintain autonomy over the pacing of activities. An integral part of empowering youth with FMS is to validate and respect their knowledge of their body and experiences. Educators can assist them in setting personal and emotional boundaries.

### 3. Optimizing functional ability

The aim is for these young people to achieve activity boundaries in which they can be as active as possible without aggravating their symptoms. Once reasonable boundaries are achieved, patients can very gradually extend their activities at their **own pace as they are able**.

## Guidelines

### 1. The treating physician is responsible for the patient's care and should oversee all rehabilitative efforts.

It is helpful if the treating physician provides a letter to educators outlining the patient's condition and limitations. Open communication and feedback is essential so that strategies can be assessed and adjusted. All rehabilitation personnel must be knowledgeable about FMS.

### 2. Educators should meet with the student and parents.

As soon as a student has been diagnosed with FMS and at the beginning of each school term, the educator should meet with the parents and student. It is very challenging for parents to care for a chronically ill child, particularly when the child has a poorly understood illness. Collaboration among educators, parents and the student is advised. Parents should be encouraged to provide written information about their children's difficulties to be given to all of their teachers.

### 3. The biological pathophysiology of FMS must be respected and reflected in educational accommodations.

- All the patient's symptoms must be taken into consideration. The complex and varied dysfunctions and their interactions must be taken into account when determining what accommodations need to be made.
- The patient's physical symptoms, cognitive difficulties due to brain dysfunction, fatigue and emotional symptoms are a biological reality of FMS.
- The patient's activity boundaries fluctuate from day to day, and even hour to hour, and s/he lacks stamina. The longer the patient has suffered a symptom, the more limited her/his activity boundary is likely to be. Patience is required because it is essential that the student does not exceed his/her limitations. Special considerations for physical education classes are particularly important.
- Educational programs must not exacerbate the patient's symptoms.

#### 4. Educational accommodations must respect the patient's autonomy, be conducive to healing, and individualized.

The severity and hierarchy of symptoms, aggravators, and activity limitations will vary with each youth who has FMS. It is important that educators be sensitive and accommodate the young person's limitations when planning her/his program.

- Accommodations must be individualized according to pain severity and activity limitation, keeping in mind the unpredictable nature of FMS.
- Sometimes a young person is unaware of early warning signs or ignores them because s/he wants to fit in with peers. An alert educator will become aware of symptoms such as pallor, general uneasiness, slowing and deterioration of speech and work, anxiety, and emotional distress, which are signs that the student is experiencing increased pain and/or becoming exhausted. An educator can empower the student by assisting him/her in recognizing and monitoring early warning signs of excessive pain and fatigue. These signs are signals from the body to modify activities or rest.
- Begin the program at a level that will ensure the student's success.
- Patients must learn self-pacing – that is, they are in control of pacing their activities. Help the student learn to pace activities with very gradual increases, only when the student feels able, in order to ensure continued success. Pacing must be flexible and accommodate times when little can be achieved.
- The learning environment should maximize healing and minimize stress, pain and overload phenomena. It should be a comfortable temperature, and free from distractions and confusion. The student's body may not be able to adequately regulate its temperature so the student may need to wear extra or lighter clothing.
- Avoid sensory and information overload and pressure for excessive speed, all of which cause rapid deterioration of cognitive processing and increased difficulties in concentrating, retrieving words and information, and multi-tasking. Forgetfulness is very common and not meant to annoy. These students will require extra time for assignments and exams.
- Keep directions simple, clear and concise.
- FMS students may need to eat or drink in class.
- If these young people stand up quickly or remain standing they can very suddenly become weak, nauseated, and disoriented. They must be allowed to remain seated if they have these difficulties.
- It is helpful for schools to issue these students two sets of books, one for home and one for school, in order to prevent avoid muscle spasms and aggravating their low pain tolerance from carrying books.

#### 5. Student participation

The student is aware of his/her own body and how s/he feels. Educators can empower the student through respect. The student's autonomy is vital to her/his physical and psychological well-being. When the student is involved in establishing priorities and strategy decisions, s/he will be more motivated to succeed and misunderstandings will be minimized.

- Involve the student in setting realistic goals.
- It is important that the student is able to establish the complexity and pacing of activities. One of the most important features of managing FMS is that the patient learns to **self-pace** activities. When the patient is in control of pacing activities, s/he can gradually explore ways to increase activities as his/her ability allows, thus increasing the likelihood of success and continued commitment.
- Rest intervals should be incorporated into the school day as needed.

- Involve the student in developing alternative strategies in preparation for times when s/he is having flare-ups.
- In order to avoid disruption of the class, the teacher and student can develop prearranged signs or the teacher can give the student a 'pass card' to show when the simple agreed upon accommodations are needed, such as taking a short walk, resting, wearing sunglasses, eating a snack to regain strength, not standing in line, or being excused to go to the bathroom. (See note at end of chapter.)

While the basic principles of educational planning are briefly mentioned here, many educational accommodations are more complex and are discussed in detail in later chapters.

It is very difficult for children and young people to live with constant pain and fatigue. School work and physical activities are challenging. These young people should be encouraged to pursue interests that they can do that they might not have pursued if their activities were not limited. Listening to stories on CDs or tapes, or writing, or some hobbies that do not require strenuous physical activity may interest them. Above all else, it is essential for their meaningful others to be supportive and understanding.

The National ME/FM Action Network website <http://www.mefmaction.net> includes a Youth Site where parents and educators can obtain further information. If you have a tip that may help others assist young people with FMS, we would like to hear from you. We also post poems and short stories written by young people with FMS. Submission guidelines and contact information are on our Youth Site. We would be most interested in receiving submissions from your students with FMS and they may find it rewarding to have their poems posted on our national website.

**Young people have the right to access education according to their circumstances. It is most imperative that parents, educators, and meaningful others remain patient, understanding, and supportive! Teaching, a demanding profession, can also offer a rewarding experience to an educator, who has the opportunity and privilege of touching the hearts and souls of these young people and making a positive difference in their lives.**

**Note:** Following a report by the Chief Medical Officer's Working Group, which stated that "Activity beyond the level that an individual can usually tolerate will prompt a delayed worsening of symptoms", the Department of Health in the United Kingdom has endorsed the use of a "pass card" to protect the health of children with ME/CFS while they are in school (20). The "pass card" has the child's photograph, is signed by the principal, and states that the child has permission to use the school's disabled facilities or obtain other assistance. Accommodations are agreed upon in advance. The child simply needs to show the teacher the card as required. The National ME/FM Action Network would like to spearhead a drive to make a "pass card" available for ME/CFS and FMS patients in Canada. If you are able to assist us or have any suggestions in furthering this cause please contact Marjorie van de Sande at [mvandes@shaw.ca](mailto:mvandes@shaw.ca)

*Most medical information in this chapter is from the Canadian FMS Consensus Document. This informative document includes the clinical definition, discussion of the symptoms, diagnostic and treatment protocols, and a research overview. Guidelines for self-management strategies, exercise, and practical appendices are also included. The document may be viewed on the National ME/FM Action Network website, and instructions for ordering the journal are provided. <http://www.mefmaction.net>*

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## Chapter 3

# Medical Aspects of ME/CFS and FMS: The Role of the Physician

By

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### Introduction

Myalgic Encephalomyelitis (ME) is a poorly understood illness affecting both adults and children, and may result in severe physical disability. In Canada and the United Kingdom, the term Myalgic Encephalomyelitis (ME) is used to characterise the disorder, whereas in the United States the term Chronic Fatigue Syndrome (CFS) is the term most widely used. Fibromyalgia (FMS) is a similar disorder with considerable overlap with ME/CFS and, according to some researchers, may represent the same clinical entity. Despite slightly different interpretations, it is my view that these three terms probably represent the same clinical condition. Since this chapter is being written for the National ME/FM Action Network of Canada, we will use the term 'ME/CFS/FMS' throughout, although most of the research we are referring to involved patients diagnosed with CFS. From a medical and educational perspective, the individualised approach to managing these illnesses is the same.

The difficulty in the medical research on ME/CFS/FMS has been an inability to find a concrete biologic marker to establish the diagnosis. As a result, we are forced to rely upon symptoms and subjective statements of disability to establish the diagnosis, a problem that has proven difficult for researchers, clinicians, educators, patients, and society in general. For persons with obvious manifestations of illness, physicians and educators provide services to reduce suffering. There is no controversy concerning the presence of illness. In the case of ME/CFS/FMS, the symptoms may be disabling, yet the person who has the illness looks well, creating doubt as to the need for extra services. It has been this paradox that has caused the most confusion about the illness over the past 20 years. It has also been this paradox, which has led some researchers and much of society to assume that ME/CFS/FMS is a psychological disorder. New research, however, is solving this paradox, and it is likely that within the next 10 years, the mechanism causing the illness will be understood. It is my personal belief that ME/CFS/FMS is a biologic disorder of the brain and of the brain stem, and it is not due to psychological factors. As with any medical illness, however, psychological factors can complicate the illness.

The social dilemmas that have surrounded ME/CFS/FMS have caused the greatest suffering for children. There has been confusion on the part of family, school personnel and even physicians as to whether the young patient is accurately representing symptoms or merely dissembling in an attempt to achieve a secondary gain. This confusion has the unfortunate effect of undermining willingness to provide treatment and services for these children. Sometimes, the presence of illness is denied by providers, with the disastrous consequences that no treatment or educational management is provided. The purpose of this chapter is to create an overview to help teachers and educational providers to understand the dilemma and create an environment where educational achievement is promoted. The situation is not very different from attention deficit disorder, where once school personnel have gained a mastery of the

condition, educational management can be well managed. It is my feeling that educational personnel will soon have a good understanding of ME/CFS/FMS and children will be allowed to reach their potential with less difficulty than has occurred in the past.

### **History of the Illness**

ME/CFS/FMS is not a new illness. During the 19th and 20th centuries numerous descriptions have occurred in medical literature, each description being subjective and employing a different name for the illness. Over the past 60 years, there have been many descriptions of ME/CFS/FMS, most frequently in the early years describing cluster outbreaks occurring around the world. Some of the best described have occurred in Los Angeles in 1938, London, England at the Royal Free Hospital in 1950, and on the northern coast of Iceland at the same time. More recently, cluster outbreaks have occurred in Incline Village, Nevada, and Lyndonville, New York, in 1985. Because these descriptions involved clusters of patients who came down with the illness, there was the widespread assumption that ME/CFS/FMS was due to an infectious agent, although, to this day, isolation of that agent has been elusive.

During the 1950's, most attention to ME/CFS/FMS was directed to polio, which remains as a model describing the illness. In infectious poliomyelitis, there are two abnormalities that occur. One is damage to the brain, which causes symptoms of tiredness, weakness and cognitive difficulties, and the second is damage to the nerve cells leading to the arms or legs, resulting in paralysis. In ME/CFS/FMS, there is no paralysis; however, the similarity of the other symptoms has been striking. Indeed, one of the names which was suggested for the illness in the 1950's was 'atypical poliomyelitis'.

It has only been recently that diagnostic criteria have been developed to by-pass some of the ambiguities involved with the earlier reporting of this illness. Because the primary symptoms are subjective, different researchers may describe them in different ways, causing confusion as to whether they represent the same or separate clinical conditions. Over the past 15 years, diagnostic criteria have been developed for adults with ME/CFS/FMS in the United Kingdom, United States and in Australia. While these criteria vary slightly, they are close enough in description to represent the same illness. At present, specific criteria for children have not been developed, causing difficulty for paediatricians and educational providers. For the time being, diagnostic criteria for adults are employed for children but there are several minor differences that will be discussed later.

### **Symptoms**

The onset of ME/CFS/FMS can occur in two different ways. It most frequently occurs in about 75% of patients as an acute illness that resembles the flu. However, instead of normal resolution over one week's time, the symptoms persist indefinitely. It is because of the frequency of this type of onset that ME/CFS/FMS have frequently been considered to be caused by an infectious agent, most likely a virus.

The remaining 25% of persons with ME/CFS/FMS have a gradual or insidious onset with the slow development of symptoms over weeks or months. The illness can occur in families giving rise to the suggestion that genetics are important. Even within families, different persons can have both the acute and chronic onset.

The first and most important symptom of this illness has been loosely called fatigue, although fatigue is a poor term. More accurately it would be "weakness", "asthenia", or "exhaustion" which limits normal activities. This limitation of activities is essential to the diagnosis and

causes the greatest disability. The activity limitation of ME/CFS/FMS differentiates it from the normal fatigue of the general population.

The fatigue is further characterized by lack of resolution with appropriate rest and worsening with exertion. These characteristics differentiate it from the fatigue of depression, where exertion and/or exercise improve the fatigue. When healthy persons have fatigue from excessive activity, it resolves given appropriate rest. This does not occur in ME/CFS/FMS. The exhaustion of ME/CFS/FMS persists despite rest, causing disability. It is possible that there are mild forms where activity is not excessively limited; however, at the present time, the diagnosis ME/CFS/FMS is reserved for those persons whose daily activity is clearly restricted by the symptoms.

Cognitive dysfunction is the second most disabling symptom in this illness. It is characterized by forgetfulness, decrease in short-term memory, and difficulty focusing and maintaining attention. There may also be deficits in arithmetic and problems with information processing and word finding ability. A child may be unable to comprehend a paragraph he or she has just read, or to follow the simple plot of a television show. The child may have difficulty remembering the way to a friend's house or directions to a game he or she used to love. These symptoms are striking in a previously healthy child who has developed the sudden onset of ME/CFS/FMS. In general, the cognitive symptoms are associated with the severity of fatigue. It is because of these cognitive symptoms that teenagers describe their inability to complete their academic assignments after a period of exertion; however, they appear to do well with appropriate rest and with taking frequent rest periods.

Other somatic symptoms include diffuse musculoskeletal pain and pain in the joints without heat or swelling. Frequent headaches, sometimes on a daily basis, usually parallel the severity of the fatigue. Sore throats are common, abdominal discomfort is sometimes described as irritable bowel syndrome and sleep disturbance, characterized by unrefreshing sleep and sleep phase reversal are usually present. Other symptoms less well characterized include the sensation of fever, excessive thirst, numbness and tingling of the extremities, light-headedness and facial pallor or flushing, eye pain and sensitivities to light, noise, and/or chemicals. The diagnosis is made when there is activity-limiting fatigue that has persisted for at least three to six months and when there is the presence of several of the other symptoms.

The severity of ME/CFS/FMS can vary from mild forms to fatigue so severe that it keeps a child or adolescent bedridden. This variation in symptom severity is not unusual and occurs in many other illnesses. Therapeutic and educational management revolves around assessment of the specific individual's severity of activity limitation. It is possible to assess this severity by measuring the amount of upright activity done during a 24-hour period. Most healthy teenagers are active 12 hours daily: school, sports, after school activities, movies, shopping, or social events. The remaining 12 hours are in sedentary activities: sleep, meals, watching TV. If the same history is taken from an adolescent who has ME/CFS/FMS, the ratio of active to resting activities is different. Frequently, they are able to have only 3-6 hours of activity during the day and the remainder of the day requires rest.

Because patients with ME/CFS/FMS look well, it is often assumed that they are just lazy or trying to avoid school activities. On questioning, however, the activity limitation occurs equally after school hours and on weekends. In their prior history as students, many have no history of emotional, behavioural or school problems and they may have had excellent grades, demonstrating that there is no secondary gain to be achieved from school absence. In children

with poor performance or behaviour problems prior to developing ME/CFS/FMS, the diagnosis is more difficult.

Medical evaluation is essential for any child or adolescent who has activity limiting fatigue. The physician will evaluate for known conditions such as thyroid disorders, diabetes mellitus, anemia, and inflammatory conditions, but the blood tests in a child with ME/CFS/FMS will be normal. Minor abnormalities occur on physical examination such as pallor, excessive facial flushing, and subtle changes in neurologic exam. Because these physical examination findings are subtle, but the disability described is dramatic, physicians and educators alike have had difficulty in understanding the pathophysiology of the illness.

At present, there are no specific diagnostic tests that will allow the diagnosis of ME/CFS/FMS, and the diagnosis is made entirely upon the symptoms and physical exam. However, in the research setting, there are several abnormalities described, some of which may soon become useful in facilitating the diagnosis. However, it is essential that other organic illnesses not be mistaken for ME/CFS and/or FMS and close supervision with the practicing paediatrician is essential.

### **Prognosis**

At the present time, the true prognosis of ME/CFS/FMS is unknown. In our office, we have followed 40 children for more than 15 years and roughly 80% have returned to a good functional state. 37% reported being free of illness and a further 40% reported having mild to moderate symptoms and activity restriction. The remaining children, however, persist with significant disability characterized by both activity limitation and severe symptoms. These children have been unable to lead a normal life style and young adults remain in their parents' households because they are unable to live independently. It should be noted that in these individuals, no alternative diagnosis has presented itself in the past 15 years and so it appears that the diagnosis of ME/CFS/FMS is both reliable and accurate. It is fortunate that the majority of young persons with this illness do eventually improve, although this may take up to 9½ years.

### **Role of Emotions**

The controversy surrounding ME/CFS/FMS has been whether the illness is medical or psychiatric. It has long been my opinion that this illness has an organic, physiologic basis and is not due to psychiatric illness. Unfortunately, the general public and even some physicians have oversimplified this debate: they question whether ME/CFS/FMS are "real" or not. As this pertains to children, bluntly speaking, the controversy has been whether children have been faking it and pretending to be sick and unable to attend school, or whether they are truly affected with a poorly understood but disabling illness. To paediatricians familiar with ME/CFS/FMS, the concept that children are faking the illness to avoid school is ludicrous.

While the cause or causes of ME/CFS/FMS are unknown, the reality of the illness is well established. It is an illness recognised by the Centers for Disease Control in the US, and the World Health Organization. More than a thousand medical papers have been published on it in the past ten years. In children, the illness can be disabling and cause severe symptoms leading to extended school absence and educational handicap. The pattern of school attendance with ME/CFS/FMS is different from that of depression. Indeed, ME/CFS/FMS causes greater school absence than is caused by known psychiatric illnesses.

There is no medical illness inherently free of emotional overlay. The treatment of diabetes mellitus in children is often complicated by behavioural and emotional disorders, and the presence of this emotional overlay in a chronic disease is to be expected. Similarly, depression may accompany ME/CFS/FMS because of the daily experience of somatic symptoms, disruption of social and educational functions, and the perceived scepticism of society that the children are "imagining" their symptoms. The depression, which may accompany ME/CFS/FMS, is estimated to occur between 40% and 75% of children and is easily recognised by the experienced clinician. Moreover it can be effectively treated with medication and supportive management. Unfortunately, this management usually does not improve the activity limitation to the degree that increased school attendance is possible.

From an educational perspective, it is important that school personnel do not express fixed opinions of the cause of the illness at this early state of our knowledge. Again the parallel with learning disabilities is appropriate: it is not necessary to understand the cause to provide good medical and educational management. As with the management of learning disabilities, it is important to assess the capabilities of the student without assuming that deficiencies are due to character flaws, behaviour problems or laziness. This type of prejudice merely causes further isolation for the young person with ME/CFS/FMS and increases difficulties in early school return.

### **Educational Management**

The goal of medical treatment in ME/CFS/FMS is to reduce symptoms, particularly the activity limitation or fatigue, and allow normal activities. Newer treatment strategies including use of certain medications have shown a modest increase in functional activities, and decrease in somatic discomfort.

The educational management of young people with ME/CFS/FMS is critical. The goal is to maintain educational objectives so that in the event of recovery, the child will not be at an educational disadvantage. In the event that disability persists, education is essential in providing flexibility to increase eventual financial independence. Therefore the goal for educators is to maintain the knowledge base for the child rather than merely insist upon school attendance.

The degree of school attendance depends on the amount of activity possible on an average day. If an adolescent has five hours of daily activity, on average, three of these hours should be spent in school and educational activities. I recommend that some of the more severely affected children attend school for one hour or less. This time does not contribute to academic achievement, but is important to maintain social contact, as well as serving as a type of "exercise therapy". The prevention of social isolation is very important.

If a child has six hours of continuous activity, full time school can be attempted without gym. Most adolescents will add gym to their schedule if they are able to. The amount of time spent in school is unique to each case and should be assessed as such. In severe cases of illness, children are unable to leave the house due to symptom severity and in these cases I recommend home tutoring to enable them to maintain as much of their academics as possible. I always prefer to have students in school so as to minimise the social disruption of the illness, but if this is not possible, home tutoring will keep them from falling behind in their studies.

Many children who are recovering from ME/CFS/FMS attempt to increase their activity too rapidly and have a worsening of symptoms. It is preferable to attend school regularly for a defined number of hours than to have erratic attendance. Generally, changes in school

attendance are made on a monthly basis. Recovery, when it occurs, is slow and marked with relapses.

Often it is the child's physician who is asked to document the child's health status and the amount of school that may be attempted. When acting as a child's ME/CFS/FMS specialist I am often called upon to write letters to the school to assist them in understanding the illness and the limitations it places on the student. These letters have assisted children in securing services, which have made the continuation of education possible. Physicians' letters can be most helpful in securing necessary accommodations for the student with ME/CFS/FMS and can help ease the school's concerns that the illness is indeed a physical malady.

Specific tasks within the school need to be tailored to the individual and many of these accommodations can be made with common sense. It is hoped that the information in this section has given you a foundation for understanding this illness and will help you in tailoring a specific educational plan for the child or adolescent with ME/CFS/FMS.

## Chapter 4

### "I Look So Normal": The Impact of ME/CFS and/or FMS on Children and Adolescents

By

**Kate Andersen, M.Ed.**

I look 'normal' so people don't believe that I could be very ill, and I didn't want to believe this, either. I want to learn, and I want to go to school but, well, the school board "sucks". They have tried to accommodate me but I always seem to fall between the cracks. I'm too smart. I can't attend on a regular basis. I'm too young to speak for myself. No one ever listens, or they do, but they just don't want to hear. - **Erin**, a 15 year old

All teachers reading her words will feel compassion when Erin says: "I'm too young to speak for myself. No one ever listens, or they do, but they just don't want to hear". Teachers know how important it is for a young person to be listened to and believed, especially when a child is suffering. But without greater knowledge about the complex illnesses, ME/CFS and FMS, how are teachers to truly comprehend that a child who looks so well is in fact very ill? How are teachers to accept that Erin truly means what she says when she states that she really does want to go to school? How are teachers to recognise that the current special educational provisions don't fit the young person with ME/CFS and/or FMS? We believe that by learning more about the way in which these illnesses affect the daily life of the child, teachers will be able to respond to children like Erin with the compassion that is in their hearts and with the professionalism of which they are proud.

#### **The History of ME/CFS and/or FMS**

Most historical accounts of the emergence of the term "ME" (myalgic encephalomyelitis) point to outbreaks of a similar set of illnesses referred to by various terms. As Dr. Bell pointed out in the previous chapter, the illness was at one time referred to as 'atypical polio'. The term 'myalgic encephalomyelitis' was first used in 1956 by Dr. Melvin Ramsay, following a series of worldwide outbreaks. In these early outbreaks ME was well documented to occur in children (MacIntyre, 1999).

When a fatiguing illness began to appear in large numbers of people in the 1980's, a group of U.S. researchers developed a new term for the condition: chronic fatigue syndrome (CFS), also known as chronic immune dysfunction syndrome (CFIDS). A consensus group also developed a set of diagnostic criteria that differed slightly from those of the original myalgic encephalomyelitis (ME). Doctors and researchers familiar with the earlier body of medical literature on ME believe that these new criteria, along with the new name, have led to a state of confusion (Hyde, 1998).

One of the problems with the creation of the new name and new definition is that people with a wide variety of problems, all characterised by fatigue, may be included in some of the recent research, leading to difficult-to-interpret results. Some of these patients may not have ME at all but a psychiatric disorder or another fatiguing condition (De Becker et al., 2000; Dowsett, 2001;

Goudsmitt, 2002). This is too big a topic to cover here but interested readers can follow it up by browsing some of the web sites listed in the reference list at the end of this Sourcebook.

Along with other misconceptions about the so-called new illness some assumed, without evidence, that lifestyle factors of the past three decades are associated with developing ME/CFS. The inaccurate and offensive term for CFS, "yuppie flu," arose from the fact that one of the big outbreaks of the illness in the 1980s occurred at Lake Tahoe, a resort where many young and upwardly mobile professionals take vacations. However, parallel with this epidemic was one in Lyndonville, New York, in which children were the first to be diagnosed with ME/CFS and FMS, and where adult patients were often poverty-stricken. However, the media latched on to the misconception that ME/CFS affects young professionals and it has been difficult to get the true facts across to doctors and the general public.

Research does not support the notion that CFS is more likely to be experienced by young professionals. On the basis of a major epidemiological study conducted in the United States, the CFIDS Association of America has reported: "CFIDS does not discriminate. It strikes people of all age, racial, ethnic, and socio-economic groups" (CFIDS Association, 2002). Renee Brehio of the CFIDS Association states, "In fact, the highest levels of CFIDS were consistently found among minority groups and individuals with lower levels of education and occupational status, such as blue-collar workers". A recent British study found cases of ME/CFS in children from all social classes (Speight et al., 2001).

Fibromyalgia Syndrome (FMS) was given official diagnostic criteria by the American College of Rheumatology in 1990. Dr. Bruce Carruthers, a Canadian physician, reports that it, too, has been described by various terms in past decades. He states that "its major and defining symptom is chronic severe widespread musculoskeletal pain, and it is much more common than ME/CFS" (MEBC, 2002). He does not think ME/CFS and FMS are 'the same' illness. He says, however, "they may overlap and change into each other in the same patient. When research has advanced to the point of clarifying how these illnesses arise", he adds, "I expect it will be obvious to all observers that they are both variants of the same type of disease".

### **How Many People Have ME/CFS and/or FMS?**

#### **ME/CFS**

The CFIDS Association of America estimates that approximately 422 per 100,000 persons in the U.S. have ME/CFS. They state that "this means as many as 800,000 people nationwide suffer from the illness but that 90% of patients have not been diagnosed and are not receiving proper medical care for their illness" (2001). As yet, there have been no government studies conducted in Canada to determine the number of adults with ME/CFS and/or FMS. However, Lydia Neilson, the President and CEO of the National ME/FM Action Network, reports that she is currently assuming that our figures are comparable to those of the United States.

When it comes to children, there are no reliable figures of the numbers with ME/CFS in the U.S. or in Canada. An early study in the United States determined that ME/CFS was clearly present among adolescents, but that the prevalence was lower than for most adult age groups. However, the researchers commented that differences in the prevalence estimates were related to differences in the designs of the studies and that the CFS case definition for adolescents needs scrutiny (CFIDS Association of America, 2002).

We are fortunate in having statistics on ME/CFS in children in United Kingdom to consider, though we cannot be sure that Canada, with its different climate, population, and other factors, would have comparable figures. In Britain, Dowsett and Colby (1997) conducted a survey of schools and discovered that there was "a prevalence in this population of 70/100,000 in pupils and 500/100,000 in staff - a rate two or three times that quoted in other adult population surveys." The authors of the British report, "Childhood ME" stated that a separate study found a similar prevalence in England, "but a significant difference of case distribution in these two neighbouring boroughs with the same populations, which indicated clustering of cases." (MacIntyre, 1999). Bell (2001) cited an Australian study, which reported 5.5 CFS cases per 100,000 children up to age 9, and 47.9 per 100,000 in ages 10-19.

## **FMS**

The Canadian Arthritis Society (2002) reports that 900,000 (3 in 100) Canadians have fibromyalgia with women being at least four times more likely than men to develop the condition. Although it usually occurs in people over age 50, and the incidence increases with age, it is well accepted that children can have FMS. Juvenile primary fibromyalgia is uncommon, but there are suggestions that its incidence is increasing. It has been reported that one study found that 1.2% of school children (all girls) met the criteria for fibromyalgia. Other studies have found an even higher prevalence of fibromyalgia in children.

## **The Impact of Medical Ignorance**

Unfortunately, both ME/CFS and/or FMS have received little official recognition in Canada, as shown by the lack of investment into research, treatment, medical education and educational policy reform. The lack of good information for doctors is the most serious problem facing Canadians with these illnesses. Although this situation creates many problems for adults, because young people rarely seek medical treatment by themselves and must rely on their parents to recognize that something is wrong, there are additional complications in obtaining diagnoses for children.

In the "Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome", Oleske et al. (2002) state:

The literature for [children with ME/CFS] is more limited than that on adults. The diagnosis of CFS in the pediatric population is complicated by the unique and changing developmental, physical, and emotional characteristics of children compared to adults. The long term impact of the cognitive abnormalities is more pervasive in the child, due to disease onset during a period of rapid intellectual development. Frustration and secondary depression are frequent components for the youth and families trying to cope with a child having an undiagnosed illness, who is always tired and unable to keep up with peers. Many physician encounters with such patients are characterized by an all too brief history, curtailed physical examination and limited laboratory evaluation. The diagnostic outcome is predictable: the patient's illness is diagnosed as depression, a psychosomatic illness, and malingering or school phobia. The outcome for the individual and family members is also predictable: conflict, confusion, and the search for a diagnosis and cure from anyone, regardless of cost or competency (p. 51).

When young people, particularly adolescents, develop unexplained symptoms, there is a tendency to look for psychological problems or to dismiss symptoms as normal aspects of adolescence:

By the end of her first year in secondary school, my 13-year old daughter, Karen, later diagnosed with mild ME, was starting to fall badly behind in her grades. I became dissatisfied with Karen's situation and requested a referral to a paediatrician. During this office visit, Karen sat unresponsive, staring into space. "She's just not with us," commented the physician. He pointed to her budding breasts and stated: "I think this is what's going on. She's entering puberty." Then, when Karen left the room to dress, he stated his scepticism about the existence of ME as an illness, commenting "After all, I am very tired, too". He said this to me, even after I had told him that I had ME myself!

The lack of figures and the lack of medical knowledge about the illnesses mean that there are probably many undiagnosed children who are struggling in Canadian schools. Such youngsters are possibly earning some very unfair labels, such as "unmotivated" or "lazy":

By the end of her first year in secondary school, my 13-year old daughter, Karen, later diagnosed with mild ME, was starting to fall badly behind in her grades. She had missed considerable school due to frequent flu-like episodes. When we contacted the school to discuss better ways of helping Karen keep up with her work, the counsellor stated that she felt Karen had "a bit of an attitude problem".

Karen's mother reported that the charge of having an 'attitude' problem was based on the fact that, in frustration, Karen had become angry with the counsellor and teacher who said, when she missed schoolwork, "find out from a classmate what you missed and catch up." The counsellor and teachers did not know that Karen could not catch up in the simple way that they suggested. Having undiagnosed ME/CFS, Karen was exhausted after school and she also had significant cognitive problems, especially with concentration, memory and auditory processing. She was also very emotional, due to the effects of the illness, and her "anger" was likely at least partly a symptom of this new emotionality (Gurwitt, 1995). Contacting friends and figuring out what work she'd missed and studying hurriedly to catch up was impossible. Karen felt absolutely defeated and yet she herself did not realise what was wrong.

Karen's mother reported that a year or so after this visit, after missing more and more school and failing her courses, Karen became suicidal. Her parents immediately asked for a referral to specialists who knew about ME/CFS. The immunologist, an adolescent psychiatrist, and a clinical psychologist then combined the results of their evaluations and determined that Karen had mild, atypical, insidious-onset chronic fatigue syndrome with a reactive depression. Alternate schooling was arranged and Karen's depression began to subside but her fatigability and cognitive problems remained. Over several years, Karen's health and grades began to improve and she graduated from her alternate school with honours.

Karen's teachers and school counsellors cannot be held responsible for misunderstanding this young student, given the fact that doctors were not able to diagnose her properly. Fortunately, things have changed somewhat in the years since Karen was diagnosed, and there is a growing international agreement about the reality of ME/CFS and FMS as serious, potentially very disabling illnesses. Doctors are becoming more aware of the way the illnesses begin in young people and are recognizing indicators and symptoms. This situation should lead to fewer instances of educational and medical mistreatment of young people like Karen. Still, families have a difficult time getting the help they need for their child. The ill child has an even harder journey. To understand what happens, let's look at how the illness starts.

## Illness Onset

When do parents first think that something is wrong with their child's health? Although children as young as five years of age have been diagnosed with ME/CFS and/or FMS, the average age of onset appears to be at about 11 or 12 (Bell et al., 2001). Both boys and girls can have ME/CFS and/or FMS. In one study (Speight et al. 2001), the female to male ratio was 2.5:1. In the follow-up study by Krilov, et al. (1998) 71% were girls, and in the follow-up study by Bell, et al. (2001) the percentage was very close, with girls representing 68.6% of the sample. These were not epidemiological samples so it is not possible to determine whether these ratios apply to the population of young people with ME/CFS and/or FMS as a whole. Although ME/CFS and FMS are more commonly diagnosed in girls, boys experience the same symptoms.

The reported rates of onset-type differ somewhat from study to study. This may relate to differences in the way to types of onset are distinguished. In a study by Bell, et al. (2001), acute onset was defined as "has an acute flu-like onset with symptom pattern occurring suddenly within a 1-week period".

Study	Acute Onset	Insidious Onset
Krilov et al., 1998	60%	40%
Bell et al., 2001	22.9%	77.1%
Speight et al., 2001	77%	23%

When the illness comes on suddenly, it usually follows a virus-like episode and, on occasion, the virus involved is identified. At first, everyone expects the young person to recover from this so-called "flu", but often the youngster just does not get better. He or she may return to school only to fall ill again, a pattern that can be repeated for months until a diagnosis is obtained.

Some develop the symptoms after a trauma, such as spinal injury. A few youngsters become extremely ill and are even hospitalised. A few never go back to school. And then, there are cases that come on gradually. A child starts to have "too many" bouts of "the flu" or periods of feeling unwell. Headaches that don't respond to painkillers often become part of the picture; weakness and muscle pain can be excruciating. Symptoms such as forgetfulness, difficulty comprehending what people are saying, difficulty expressing one's meaning, problems doing simple calculations, inability to concentrate, heightened sensitivity to sound, smells and chemicals, and mood swings or episodes of anger or weeping, can become very alarming and very disabling.

Dr. Elizabeth Dowsett, a leading ME researcher from Britain, points out that it is important to remember that ME/CFS is a *syndrome* (a linked group of symptoms). She adds that it usually follows a common virus infection, which is hardly noticed. This viral illness seems to be just a typical cold or 'stomach flu' with headaches, malaise and dizziness. Most people seem to recover from this infection. However, after a time in some people, including children:

...a second more serious multi-system disease can develop with variable involvement of cardiac or skeletal muscle, liver, pancreas, lymphoid or endocrine organs. Nevertheless, ME is primarily a neurological illness with well-documented encephalitic features and classified as such by the WHO [World Health Organisation] international classification of diseases (ICD 10).

Reading this, you may be surprised to learn that an illness associated with flu-like feelings, a host of physical symptoms and fatigue is primarily neurological and has "encephalitic" features, that is, symptoms known to occur in encephalitis, or brain infection. However, appreciating this aspect of ME/CFS will help you to understand the difficulties facing children who fall ill with it, whether suddenly, or over time.

Karen's mother, herself a person with ME/CFS and FMS, began raising questions as to whether Karen might also have the illness when her daughter was about eleven years old. At this time, Karen began missing a great deal of school due to unexplained flu-like illnesses. Karen was also becoming very sensitive emotionally. Because she would break down into tears easily on the playground, her teachers and doctor felt that peer relations were the cause of Karen's problems attending school. Karen also struggled greatly with math and music, and eventually quit her music lessons in despair. When her parents discussed these issues with Karen's teacher they were reminded that not all children can be good at everything and that they should stop comparing Karen to her very bright older sister.

With hindsight, you can see that Karen had symptoms of ME/CFS many years before she was diagnosed. You can also see how doctors and others could misinterpret those symptoms, believing they arose from psychological factors. The meaning of early symptoms in insidious onset cases is still being debated by researchers. This is in spite of the fact that doctors who've had thousands of patients with ME/CFS and/or FMS have seen these patterns many times and have noted that both types of onset can occur in the same family (see Chapter 1, Medical Aspects of ME/CFS and FMS).

Obviously, all this confusion is very stressful and worrying for families and young people. Teachers can help by not jumping to conclusions and by being open to various possible causes of a child's problems. A child might appear to be having behavioural, learning or emotional problems but in fact be heading for a diagnosis of ME/CFS. Or a child may just not be as good at math as her sibling or may have some physical or psychological symptoms that have nothing to do with ME/CFS. Teachers can also help by passing on their observations of the child to the parents. "Marc seems to miss some of what is going on. Might he have a hearing problem?" is a useful observation to make to parents, presented in a sensitive way.

A complicating factor in diagnosis is that a child's own lack of awareness of the symptoms may lead to youngsters not talking about them or denying their presence:

The diagnosis is more difficult in young children because they cannot articulate symptoms such as fatigue and cognitive difficulties. Parents and teachers need to observe and assess symptoms such as onset of pallor and exhaustion, both in and out of school. Their observations of children or pupils whom they know well should be respected. (MacIntyre, 1999).

Many [young people with ME/CFS and/or FMS] have no memory of being completely well and are therefore not sure what health is and what illness is. Adults who became ill as children have stated that they are in good to excellent health while disclosing a significant number of current symptoms....

...Younger children, who learn at such a rapid pace, have not yet become aware of their learning strengths and weaknesses, making it almost impossible for them to judge the cognitive problems they may be experiencing (pp. 68-69).

Dr. Bell and associates (1999) have described this lack of awareness that they are ill in some people as "health identity confusion". Health identity confusion may be more likely to arise in children who had insidious onset.

Marc's mother reported:

Marc was identified as having fibromyalgia and chronic fatigue syndrome when he was about 12. The clues had been piling up since kindergarten but no one had put them together. The kindergarten teacher observed Marc's aversion to printing and colouring. In the early grades, he developed strategies for avoiding written work.

One teacher suggested he should repeat the grade because of his delays in writing. Fortunately, the occupational therapist who was called in advised the school that this was a long term condition, that little could be done to correct it, and that it was up to the school to accommodate it. However, even he did not recognise the physical pain and discomfort Marc felt when holding a pencil or pen.

The kindergarten teacher suggested we have Marc's hearing tested. Subsequent teachers made the same request noting that, though he was bright, he didn't always seem to pick up what was going on in class. According to the tests, his hearing was normal or better. The kindergarten had flagged a possible short-term memory problem. We came to suspect an auditory processing problem and arranged for an educational assessment. The test results were not as clear-cut as we had expected. We still didn't realise we were dealing with the more complex 'brain-fog'.

In the early grades we found that Marc suffered from headaches. He seldom complained about them, possibly because he had suffered from headaches for so long he didn't know they weren't supposed to happen. We also became aware that he had significant allergies, a fairly common occurrence in those with ME/CFS or FMS.

We did not appreciate how tired Marc felt, though one teacher commented two years after she taught him that tiredness was a big problem. We did notice that he was irritable when he came home from school. We were concerned about the amount of time he spent playing computer games or watching TV, not realising that these activities stimulated him without wearing him out. We remember particularly the tremendous fights we had over homework. How he resisted doing homework! When he did it, it took forever. I remember pushing him to complete his work one night and seeing the look of frustration or desperation on his face as he sought to make me understand he was already giving 200% effort. That look still haunts me.

Grade school was not a time of fun and accomplishment for Marc. However, we were fortunate that his teachers treated him with kindness and respect, that they found ways of accommodating his problems, and that they discreetly discussed their concerns with us.

Even when a young person does feel ill and describes symptoms, part of the problem in obtaining a diagnosis is that the symptoms differ somewhat in young people from adults. There can be misconceptions about whether the symptoms reported really add up to ME/CFS and/or FMS. Here's what is stated in the British report, "Childhood ME":

Special diagnostic criteria for children and adolescents have not yet been defined. The diagnostic criteria for CFS in adults (Fukuda 1994) were defined chiefly for research purposes. Young patients may not always fulfil CFS criteria, and yet still have a typical clinical picture of ME/CFS... There are some clinical features in children that are different from those in adults, especially in children under 10 years of age. The onset is often more gradual in young children, and their daily behaviour is more variable, without a clear history of an initiating infection. Certain symptoms - intractable headache, abdominal pain, loss of appetite, and nausea - are more common in children. There is no clinical difference, once the illness is established, between children whose onset is rapid, usually following an acute febrile episode, and those with a gradual onset, as is seen more often in young children.

Especially problematic for children is the criterion of 6 months of activity limiting symptoms required of adults. MacIntyre and associates (1999) recommend that a child and family allow for a firm diagnosis after 2 to 3 months of symptoms, instead of the minimum of 6 months as required for adults. This is because good management can start early in the illness and might prevent further deterioration.

Even three months of waiting to know what the diagnosis is can be a terrible ordeal. These young people need immediate help - especially with schooling. Teachers can help greatly by doing what they can to make educational accommodations, even if a child is not yet diagnosed and does not yet have 'special needs' status. Doctors can help by writing letters that enable schools to provide services for the 'at risk' child.

Some young people become ill suddenly, sometimes literally overnight. This is what happened to a young Quebecois.

Emilie was born in the winter of 1981. Emilie first got ill March of her grade six year when she had just turned twelve. It was very sudden with her seemingly healthy one day and sick the next. She complained of not feeling well while at skipping practice. She was on a skipping show team and had a strenuous two-hour practice. I brought her home early that day as she complained of a headache and was terribly pale. The next day she woke up with a headache, upset stomach and she was very tired. Every day afterwards she got worse not better over a month. Many blood tests and family doctor visits later, we were none the wiser of why she was ill for so long. Then over Easter she felt better even though she was fighting off a cold.

After Easter holidays she went back to school for one month. In the middle of the day, one Tuesday I had to pick her up because she felt exactly the same once more. After more doctor visits, finally I had my husband come along so there would be strength in numbers and the doctor would have to take us seriously and really look into why Emilie was so sick once again. She unfortunately looked so healthy at the time. However, she was too weak and exhausted to get off the couch for anything for most of the day. The family doctor then set up an appointment with a big city paediatrician who took loads of blood from Emilie and probably tested for everything under the sun. Everything came back negative. We were given the advice to just let her rest and not to push her (previous advice was to push her some so that she would get over the initial tiredness of long lasting post-viral illness) and she would eventually get over this 'mono' type virus in time. Sure enough she did get better and was 100% healthy all summer. She made it to 4 days of grade seven then we went to a family picnic where she ran, swam, played volleyball and trampoline.

She was doing fine until she fell off a swing. She got an immediate headache and became ill from then on. Same as before except worse and chronically consistent and she has never has regained her health since. Three months later she went to a paediatric immunologist who diagnosed her with CFS.

Imagine being Emilie, an active, happy, twelve-year old. Suddenly, without warning, your life has changed completely. How terrifying the experience must have been for this young girl. Imagine being taken from doctor to doctor and having all those tests, necessary though they may have been. Imagine getting well and having a great summer, only to be knocked down with the illness again. Imagine Emilie's despair when she did not get better, though the doctor kept assuring her parents she would.

Su Lin is another young Canadian who had acute onset. In her case there may have been an early viral trigger but the real culprit seemed to be two immunisations:

My 17-year-old daughter, Su Lin, has missed 5 years of school. Looking back she has probably had ME (and FMS) since the age of 6 years following a mono-like illness. She had her challenges but was able to do well in school and was an active child (sleeping many hours after activities and suffering much pain) until at age 12 she had a Hepatitis B immunization and flu shot in the same week. (She is asthmatic). Minutes after the flu shot she went on a downhill slide and has never fully recovered. She was totally bedridden for a couple years and is still homebound. She is gradually doing better, however her cognitive abilities remain very challenged. Once an A student she can not read or write more than what you would see in a greeting card.

Michael's onset of FMS followed a flu-like illness:

Our son, Michael, now age 10, has FMS. Briefly, he developed FMS from a flu-like illness, possibly from portable mold exposure. It took 9 months of going through the usual round of clueless doctors before getting a useful diagnosis from a great doctor. The school was very understanding of his absences, but were not forthcoming about his right to home tutoring support.

When you read the account of Michael's and Su Lin's onset, you can understand why parents of children with ME/CFS and/or FMS can't say for sure when their child's illness began. You can see why they can feel so anxious about supposedly simple issues, such as Hepatitis B immunisations and flu shots. You can see why parents worry about the quality of air in classrooms and the presence of mould. Imagine if you suddenly wondered whether all the things that are supposed to protect your child from illness might cause more illness instead. Imagine how it feels to see school buildings as dangerous, instead of safe, environments for a child.

### **ME/CFS and/or FMS Can Run In Families**

Research has found the illness sometimes runs in families with as many as 15% of young people with ME/CFS having a history of another family member with the illness (Oleske et al., 2002). There may be a genetic component. Stuart is a youngster from the province of Quebec whose mother also had ME/CFS:

My son who is now 17 years old has had CFS since he was 6 years old. I, his mother, have been quite ill with CFS for 13 years. In fact it started with a virus that made the whole family ill and we trace his problem to that time although it emerged slowly as it does with children that young. He was formally diagnosed with CFS at 9 years of age but we had suspected this was his problem. If I hadn't been so ill and so well informed of CFS, a diagnosis might have been much more difficult.

In Stuart's case, the whole family fell ill at the same time, and although some recovered, at least two family members went on to develop ME/CFS. A genetic difference in the immune system, perhaps predisposition to autoimmune illness, may be involved in some families (Itoh et al., 2000). In Speight et al.'s (2001) study, there was a positive family history of CFS in a first degree relative in 7 cases (14%), a past history of migraine in 33 cases (67%), and a positive family history of migraine in a first degree relative in 28 cases (57%). (It is well known that autoimmune illnesses affect more females than males and it is possible that this factor is the explanation for the higher number of females affected in both adults and young people.)

Many parents who see symptoms of ME/CFS and/or FMS in their children have been accused of overreacting or imagining things. Karen's mother wishes the doctors had believed her sooner. You can imagine how angry she becomes remembering how her concerns were treated. What about the parents who have no experience of the illness? They may never suspect that their child has ME/CFS and/or FMS. As a teacher, you can help by remaining open-minded and objective, reporting what you see happening in the classroom. Your objective record of a child's lack of energy, drop in achievement, forgetfulness, and problems finishing work might be the information that will help the doctor reach a conclusion. The school nurse can also help you to identify children who may have ME/CFS and/or FMS.

### **The Spectrum of Illness**

There is a range of illness severity in ME/CFS. Diagnosis can be especially difficult to obtain when a child has a mild or atypical presentation. Some young people with ME/CFS may have quite a few days when they can be active for some of the time. Very severe cases, however, are devastating:

The more severe forms of the illness in children and adolescents include symptoms such as dizziness, unremitting headache, severe muscle spasms that may require splinting to prevent contractures in the hands or feet, shaking episodes or pseudo-seizures without loss of consciousness, difficulty swallowing and paresis or paralysis of limbs, bladder irritability and a disturbed mental state. (MacIntyre, 1999).

It is also important to recognize that children and adolescents with a milder course and those who have partially "recovered" may have more physical energy but may be plagued by ongoing and very handicapping neurocognitive and learning problems. To understand the impact of the illnesses on children, we have to understand its symptoms.

### **Common Symptoms and Signs**

This sign and symptom list comes from the British report "Childhood ME":

1. The most common feature for diagnosis of ME is persistent fatigue. This is better described as exhaustion, asthenia or weakness, which is usually post-exertional, developing up to 3 days following moderate effort, and is not relieved by rest/sleep. The fatigue may appear as orthostatic intolerance (dizziness or faintness when upright) rather

than simple tiredness or sleepiness. The fatigue may be physical or mental, can be severe and often fluctuating, and leads to significant reduction in normal activities.

2. Severe malaise (feeling 'poisoned'), particularly following physical or mental exertion.
3. Persistent headache, not responding to painkillers.
4. Disturbance of normal sleep pattern. Hypersomnolence is commonest initially, often progressing to sleep reversal, or else insomnia.
5. Neurocognitive disturbance is invariably present (e.g. loss of attention, concentration, and short-term memory, forgetting names, inability to understand a written paragraph).
6. Visual disturbance (eye pain, blurring, especially when reading).
7. Sensitivity to sound and/or light.
8. Recurrent sore throat and/or swollen glands (misleading in children, who develop them with every infection. Prolonged adenopathy may need investigation to exclude TB or malignancy).
9. Muscle or joint pain, especially of lower back and lower limbs.
10. Nausea, abdominal pain, loss of appetite.
11. Balance disturbance, or dizziness on sudden change of position.
12. Altered subjective temperature regulation (inappropriate sensations of fevers or chills, night sweats), and maybe objective reversal of sleep/temperature rhythms.
13. Facial pallor, especially with the onset of severe fatigue (Ramsay 1986).
14. Altered skin sensitivity, paraesthesiae (numbness, tingling), transient rash.
15. Mood changes (irritability, depression, anger and frustration) that are out of character.

### **New Knowledge About Key Symptoms**

Orthostatic Hypotension: In the past few years there has been a dramatic increase in research on a group of problems in ME/CFS and/or FMS related to blood pressure. In "Chronic Orthostatic Intolerance", Dr. Frank Albrecht, an American counsellor with special knowledge of ME/CFS and/or FMS, has listed the various names for these problems as: postural orthostatic intolerance, dysautonomia, neurally mediated hypotension (NMH), neurally mediated syncope, orthostatic syncope, postural tachycardia syndrome (POTS). Stewart, et al (2002) states: "POTS is considered to underlie orthostatic intolerance in the large majority of adolescents with CFS" (p. 32).

Although these problems can exist without the presence of ME/CFS and/or FMS, they are commonly found in adolescents with ME/CFS and/or FMS and are not unknown in younger children. For the purposes of this Sourcebook, we will refer to these symptoms as chronic

orthostatic intolerance (COI). One of the best descriptions of the effects of COI is provided by Dr. Albrecht:

In all of these conditions, upright posture makes the person sick. Walking and running are actually easier than standing or sitting still.

The symptoms caused by standing or sitting may include any of the following: fainting, dizziness, nausea, feeling very tired, feeling excessively jittery, having difficulty concentrating or remembering things, experiencing pain in the lower parts of the abdomen or in the legs, mottling or purpling of hands, ankles, feet and legs, hot flushes, sweating, and headache.

The underlying cause is a disruption of the autonomic nervous system. This system automatically regulates bodily functions, including heart rate and blood pressure. It also responds to postural or orthostatic stress. Blood is a liquid. It tries to flow downward. When you are standing it tends to run into your legs and feet. This deprives your upper body and, especially, your brain, of an adequate blood supply. The autonomic nervous system prevents this by regulating how the heart beats and by constricting blood vessels in the lower parts of the body, forcing blood upward. In people with COI, this system doesn't work right and blood tends to pool in the belly, legs, and feet. It will pool in the hands, too, if the arms are dangling. This is what causes the mottling or purpling of the skin usually seen in COI.

When the blood pools in the lower parts of the body, the heart tries to compensate by beating more rapidly. But because the blood isn't flowing correctly to the heart and brain, efficiency drops and things get worse. In many cases this leads to a sudden drop in blood pressure, which may cause severe symptoms and even fainting.

The fast heartbeat typical of upright posture in COI is called "tachycardia." This is why the condition is often called Postural Tachycardia Syndrome. Low blood pressure is called hypotension.

Most people with COI have normal blood pressure when it is taken in a doctor's office. The sudden drop in pressure typical of NMH can only be detected when it happens--after the person has been standing or sitting quietly for a period of time (several minutes to an hour or more). By the time this happens the person is already feeling sick--dizzy, tired, or in pain--from postural stress.

Many people with severe COI have Chronic Fatigue Syndrome too. And those with CFS frequently (but not always) have COI. I don't know why this is. And nobody knows what causes COI itself (though it does often get suddenly worse following a viral infection).

### **Low Blood Volume**

Recent research has found low blood volume in people with ME/CFS and a relationship between COI and low blood volume (Streeten & Bell, 1998; Streeten et al., 2000; Stewart & Weldon, 2001). Joan Livingston reports that Dr. Bell suggested that the low blood volume could help account for the prevalence of orthostatic intolerance (worsened symptoms upon standing) in CFIDS, because the limited amount of blood tended to pool in the legs and feet, with a corresponding drop in the amount available to the brain.

The result? There is a common sensation of overwhelming gravity and of wearing lead boots. Other research has added to the mounting evidence that this is a core problem in CFIDS, including reduced cerebral blood flow on SPECT scans and neurally mediated hypotension on tilt-table tests.

This new knowledge about COI and low blood volume will help teachers understand why many youngsters with ME/CFS and/or FMS adopt special postures in the classroom. While these postures may sometimes be misinterpreted as slouching or rudeness, it is likely that youngsters feel better when they sit or stand this way, without realizing why.

Sitting with the legs tucked up is a posture commonly adopted by our adolescent patients long before they understand why it has become their habit. Sitting in a low chair is helpful because it causes the legs to be brought up toward the abdomen, and probably reduces the amount of blood pooling in the intestinal circulation. Conversely, sitting in a high chair with the legs dangling freely should be avoided, as there is no resistance to blood pooling unless the leg muscles are actively contracting. One young woman we know found she could sit longer without symptoms if she put her feet on a low foot rest (this probably required more leg muscle contraction than regular sitting, and may have also compressed the abdomen better). (Rowe, 1997, Reducing Symptoms During Upright Posture).

Along the same lines, some have suggested that the urgent need to lie down felt by people with ME/CFS and/or FMS relates to the same problem of blood pooling in the legs. The awful feeling of brain 'drain' that occurs can often be relieved only by lying down. It must be noted that sometimes relief does not occur in this position and the person lying down can feel very ill and sometimes, paradoxically, unable to relax, think clearly, or sleep. Therefore, even a rest in the nurse's room may not restore a young person sufficiently to be able to return to class.

### **Understanding the Special Fatigue of ME/CFS and/or FMS**

One of the biggest issues that can complicate both teaching and diagnosing children has to do with the fatigue that is a central symptom of ME/CFS and often accompanies FMS. Teachers need to understand the quality of this fatigue and how it "works". Dr. Bell stated in Chapter 1 that a better word for the fatigue of ME/CFS and/or FMS is "asthenia". Here is a description of this asthenia, published by an advocacy organisation in British Columbia:

#### **Low Energy Reserves**

It is difficult for some to understand the fluctuating energy levels associated with ME. But it helps to understand energy levels in ME in terms of bank savings and spending. While a person with ME may be able to attend a concert like anyone else, that effort may drastically deplete their energy reserve for a while.

It's like they could afford the \$50 ticket, same as a millionaire, but once that \$50 is spent, they have nothing or little left for anything else, whereas the millionaire can keep on spending with no serious consequences.

Likewise, a person with ME may appear to have the same amount of energy in a given situation as a healthy person, but that doesn't mean they can sustain similar levels of activity over time as a healthy person can. And it may take a long time for their energy reserve, like a bank account, to build up again to allow them another activity 'spree.'

### **Absurd Assumptions**

Not understanding this principle of inconsistent energy levels, many doctors and psychologists who assess people with ME assume that if they show any evidence of being able to do any little thing they therefore can work full-time! So if a person with ME drives to an appointment, doctors may assume they can drive everyday and in all conditions. They don't understand that the drive and the appointment may wipe the person out for days afterwards.

Making these kinds of assumptions is as absurd as seeing a person dashing for half a block to catch a bus and assuming they can therefore also run a marathon! To avoid jumping to similar absurd conclusions, doctors need to carefully ask people with ME about their energy limits; e.g., how often they can drive a car and in what conditions and at what subsequent energy and pain costs to themselves! (MEBC, 2002).

Now take this very accurate description of the 'fatigue' in ME/CFE and/or FMS and apply it to a young person trying to grow up, play, see friends, join in on the family fun, and go to school. You can see that this student may not in fact be exhausted all the time. If he or she uses some energy from the reserves, however, for attending school, for example, there will be a payback later. If that payback is an hour or so of exhaustion followed by recovery and a good night's sleep, things are not too bad. That's how it was with Karen after about three years of the illness. Remember, Karen had mild ME/CFS and no FMS. However, if the payback is very great, the child may not be able to sleep that night (a common, paradoxical phenomenon in ME/CFS and/or FMS) or attend school the next day. This is a very big price to pay for attending school for a couple of hours. In time, the relapses can start to blend into each other, as happened with Emilie, and a persistent and chronic state of disability is the result. The "crashes" that young people with ME/CFS experience have numerous triggers, including exposure to chemicals, loud noise, immunisations, studying hard, and even mild physical exertion.

### **The Neurocognitive and Learning Problems May Be the Most Disabling Symptoms**

In "Does ME Cluster in Schools", Dr. Elizabeth Dowsett has stated:

Of all the symptoms associated with ME/CFS, disturbance of cognitive function is the most disabling and long lasting in both pupils and staff. It induces prolonged difficulties in maintaining wakefulness and attention, in concentration and memory, in language and mathematical ability and in appreciation of shape and judgement of distance, which, combined with motor dysfunction affecting balance and fine motor control, interferes with practical tasks and independence.

There is not yet scientific agreement about the nature and origins of the cognitive problems in ME/CFS and/or FMS, nor about how disabling they are. However, this state of uncertainty should not prevent Canadian teachers from doing their best to address these problems, on an individualised basis, in educational planning and teaching. (The discussion of cognitive problems in this section is limited to what is known about the cognitive and learning problems in children and adolescents with ME/CFS as there is very little research on such problems in FMS alone. However, in deference to Dr. Bell's view that FMS may be the same condition as ME/CFS, teachers may consider applying the recommendations about neurocognitive problems to the child with FMS.)

## Brain Injuries

In Chapter 1, Medical Aspects of ME/CFS and FMS, Dr. David Bell wrote: "It is my personal belief that ME/CFS and/or FMS is a biologic disorder of the brain and of the brain stem, and it is not due to psychological factors." It has been difficult for doctors and the general public to accept the idea that children and adolescents can have ME/CFS and/or FMS. The idea of an illness involving a virus that injures the brain in children is particularly alarming. Yet polio is another illness that begins with an encephalitis, or brain infection, and which seemed to single out children so much that earlier in this century it was called "infantile paralysis".

As we mentioned earlier, ME/CFS was once referred to as "atypical polio". Indeed, the majority of people, including children and adolescents with ME/CFS, experience a sudden onset of their symptoms and many report a viral-like illness at this time. Since the emergence of the post-polio syndrome (PPS), one research team has been exploring links between ME/CFS and PPS (2002, in press; Bruno et al., 1996, 1998a, 1998b). In polio, it is known from autopsies that the poliovirus injured the brain (Bruno, 2002, in press; Bruno et al., 1996, 1998a, 1998b). A consistent finding in brain scans of adults with ME/CFS is reduced blood flow to the brain stem (Costa et al., 1995). The cause of this reduced blood flow is not known but Bruno and associates (1998b) have discussed evidence that viral agents other than the poliovirus, such as the Coxsackie virus, selectively target the brainstem and subcortical areas of the brain, such as the basal ganglia.

Although there were reports in the 1980s that ME/CFS was a form of chronic mononucleosis initiated by the Epstein-Barr virus (EBV), larger studies did not support this idea. However, Oleske and associates (2002) point out that a complication of mononucleosis in older children and adolescents can be a prolonged, fatiguing illness. They state that "there is ... a general lack of appreciation as to how severe and prolonged a bout of acute EBV mononucleosis can be for the older child and youth." They state that, however, "older children and adolescents with post-infectious related fatigue frequently recover and do not progress into adulthood with CFS" (p. 52).

Among the other viruses currently being explored as a cause of ME/CFS is HHV-6 (Ablashi et al., 2000). It is noteworthy that this virus, which is very common, has been implicated in a wide array of problems (Kleinschmidt-DeMasters et al., 2001). It is known to cause an encephalitis, or brain infection, in some adults and children (Juntunen et al., 2001; Kerr et al., 2001). In addition to ongoing viral research (e.g. Levine, 2001), current areas of investigation include an exploration of the role of chemical exposure, mycoplasma, autoimmune processes, and neuroimmunological factors (Vallings, 2002 ). Some of these theories are compatible with theories of viral injury to the brain. For example, Hyde (1998a) has suggested that injury to the brain from chemical exposure increases the susceptibility of the brain to enteroviral infection through its damage to the blood/brain barrier.

Although all of this research is intriguing, most researchers consider that the cause(s) of ME/CFS and/or FMS has still not been established definitively. Instead, researchers are focussing on identifying consistent and characteristic symptoms in the hope that effective treatments for them can be found. Rosamund Vallings (2002) summarised one of the most recent and authoritative overviews of ME/CFS presented by Dr. Anthony Komaroff at the December 2001 Sydney ME/CFS Clinical and Scientific Conference in Australia:

Using neuro-imaging techniques, MRI has revealed punctate areas of abnormality in 78% cases, particularly in the subcortical areas. SPECT scans have shown defects in perfusion and metabolism.

...there are differences in cognition, not explained by co-existent psychological disorders; in particular there is abnormal cognitive processing and slowed reaction times.

...There is evidence of autonomic dysfunction, with sympathetic and parasympathetic neuropathy. 50% patients have signs of neurally mediated hypotension or postural tachycardia syndromes.

Most patients have sleep disorder with alpha intrusion into delta wave sleep.

There is evidence of neuro-endocrine dysfunction as shown by changes in the HPA axis. Studies have demonstrated reduced CRH production with smaller adrenal glands and a decreased 24 hour urinary cortisol level. Prolactin and growth hormone levels may also be lower.

The effects on the brain are non-destructive and non-progressive, but cause marked dysfunction.

Dr. Vallings (2001) also reported that objective evidence of brain impairment by chemical exposure was presented by Kilburn, although she does not state whether his sample included children.

He described 4 categories of responses relating to brain function: physiological (eg balance, reaction time, vision), psychological (eg problem solving, recall, memory), emotions, feelings, mood states (eg depression, anxiety) and symptoms (eg headache, sleep disturbance etc). 8 physiological and 11 psychological tests were described to assess brain function, and are usefully applied to those who have been chemically exposed. Illustrative examples were discussed, and computerised measuring tools were demonstrated.

Also summarising studies conducted on adults, a recent review of the neuropsychological research on CFS emphasised:

- slowed processing speed
- impaired working memory
- poor learning of information. (Michiels & Cluydts, 2001).

These researchers reported that no specific pattern of brain abnormalities has been found that uniquely characterises ME/CFS patients. They also comment that "there is no overwhelming evidence that fatigue is related to cognitive performance in CFS, and researchers agree that their performance on neuropsychological tasks is unlikely to be accounted solely by the severity of the depression and anxiety" (Michiels & Cluydts, 2001).

Previously, clinicians have reported a wide range of neurocognitive problems in people with ME/CFS. Curt Sandman, director of research at the State Research Institute and Professor of Psychiatry and Human Behaviour at the University of California at Irvine concluded that in ME/CFS patients "...we see a pattern that reflects memory consolidation difficulties. Memories that are made are very fragile. These patients are tremendously susceptible to memory overload and there is minimal visual sequencing deficit, as well as some attentional deficit. They also have a tendency to overestimate performance" (National CFIDS Foundation, 2002). Dr. Linda Miller Iger lists among the neurocognitive problems in adults:

- word blocking (not being able to find a word)

- word transposition (putting the wrong word in)
- fogginess
- forgetfulness
- directional problems
- acalculia (an inability to do even simple mathematical problems)
- anomia (inability to match names and faces)
- visual spatial problems (e.g., inability to judge distances...)
- auditory verbal memory disturbances (inability to follow spoken directions)
- impaired judgment
- inability to link auditory and visual input, (e.g., distracted by sounds...)
- dyslexic-like symptoms (letter reversals)
- difficulty maintaining attentional set (inability to remain on task)
- difficulty/impairment in inputting, encoding, and retrieving information
- difficulty comprehending and remembering what has been read).

### **Brain Research and Children**

Children's brains are growing and changing rapidly from conception through late adolescence. The brain of a child is different from the brain of an adolescent and the brain of an adolescent is different from the brain of an adult (Thompson et al., 2000). Consequently, it is not appropriate to generalise from brain studies of adults with ME/CFS to children and adolescents with the illness. While a similar array of neurocognitive problems have been reported in children with ME/CFS and/or FMS, unfortunately, there is barely a handful of studies of brain function in children and adolescents with ME/CFS to establish whether these reports are accurate.

In a brain scan of 13 adolescents with CFS, Goldberg and associates (1997) found reduced blood flow in several areas of the brain. They comment that there may be some overlap between this group of children and those with attention deficit disorder, especially "quiet ADD" (presumably ADHD without hyperactivity). Japanese researchers found several areas of brain difference in 3 children with CFS (Tomoda, et al., 2000).

There is a report from Australia of a study in which "there was a very strong change in cerebral blood flow in patients." The study showed a reduction in blood flow to the brain's insular cortex, which governs the smooth muscle in the gut which likely explains stomach and bowel symptoms in people with ME/CFS (Co-Cure, May 3, 2002). There was also a 20 per cent reduction in blood flow to the left lateral temporal lobe in young people with ME/CFS. This finding may relate to the difficulty severe sufferers often experience expressing themselves as that area of the brain controls access to words. At the time of this writing it is not known whether these findings have undergone peer review.

In a psychophysiological study of adolescents with ME/CFS conducted to date, attention deficits were found in youth who were free of psychiatric disorders (Bruno et al., 1998a). In an interview (Andersen, 2002a), Dr. Bruno reported:

We did the first study of the psychophysiology of young people reporting chronic fatigue using the same techniques we used to test polio survivors with fatigue. We evaluated thirty-eight young people reporting fatigue and studied thirteen subjects, who were on average 16 years old and met the 1994 Centers for Disease Control diagnostic criteria for Chronic Fatigue Syndrome. We also studied 10 non-fatigued control subjects. We gave 12 neuropsychologic tests of attention and did EEGs and found three things. First, 75% of the young people with CFS had no psychiatric diagnoses at all, not even an adjustment disorder with depressed mood. This finding

disproved the notion that ME/CFS is a psychiatric disorder that could not and should not be diagnosed in children.

Second, subjects' reports of difficulty staying awake during the day and difficulty concentrating -- the same symptoms reported by adults with ME/CFS and polio survivors with fatigue -- uniquely predicted the diagnosis of CFS, and difficulty staying awake during the day, concentrating, and focusing attention were significantly correlated with daily fatigue severity.

Third, scores on four of the neuropsychologic tests of attention were clinically abnormal in the CFS group, while scores on two additional tests of attention were statistically significantly lower in the CFS subjects and significantly correlated with daily fatigue severity. There was no difference in EEG between the two groups, probably because the age span of the subjects caused their differing basal EEG frequencies to obliterate changes related to ME/CFS. So in terms of symptoms and impaired attention - signs of brain activating system damage - ME/CFS kids looked just like adults with ME/CFS and fatigued polio survivors.

Dr. Bruno explains his "brain fatigue generator model":

The striking parallels between the history, signs, symptoms and physiology of post-polio fatigue and CFS caused us to propose the Brain Fatigue Generator Model of all post-viral fatigue syndromes. The Brain Fatigue Generator Model says that feelings of fatigue are normal and are generated naturally when neurons in the brain stem and basal ganglia become "tired" during the course of the day. These neurons stop stimulating the brain and the result is the feelings of fatigue -- difficulty paying attention, not wanting to get out of a chair -- and the overwhelming desire to just slip between the sheets and go to sleep. After a good night's rest, the brain activating system neurons recover and fatigue disappears. But chronic fatigue is not natural and is not relieved by sleep, because fatigue is generated when brain activating neurons have been damaged by a virus, such as the poliovirus or a Coxsackie virus. (Andersen, 2002b)

Chaudhuri and Behan (2000) have presented a similar model of central (brain-based) fatigue "due to a failure in the integration of the limbic input and the motor functions within the basal ganglia affecting the striatal-thalamic-frontal cortical system." They suggest that this type of fatigue is common to a number of different neurological illnesses, including ME/CFS.

### **Brain Function and Cognition**

Colby and Jacobs, in "ME and Learning: Problems and Solutions", provide a useful working model for understanding how cognition is impaired in ME/CFS and/or FM:

What impairs the thinking processes? Michael J. Goldberg's NeuroSPECT imaging has demonstrated abnormalities in blood flow (perfusion) through the brains of children with ME (1997). Dr Goldberg explains: "The importance of defining perfusion lies in the observations that cerebral function and perfusion are directly correlated." In other words, we need oxygen to think.

Brain function and fatigue in children and adolescents with ME/CFS and/or FMS are areas calling urgently for more research. While we are waiting for that research, we must accept the reports

of cognitive problems made by groups of clinicians who have worked with many children with the illnesses. The authors of the British report "Childhood ME" identify the following problems:

**Language:** listening, speaking, understanding:

Language use may be severely impaired. The pupil may lose access to a whole range of vocabulary, being unable to recall simple words, and may find difficulty with written words.

Problems with speaking may include slurred speech, the reversal of word order and the speaking of different words from those intended.

Pupils may listen to a teacher's explanations, recognising each word separately, without being able to deduce any meaning from the combination of the words into sentences, as if the teacher were speaking in a foreign language.

Speaking can be difficult and exhausting for a pupil with ME. The pupil may forget vocabulary or may speak quietly and slowly, because it is too physically exhausting to project the voice more loudly. This can be wrongly interpreted as depressive behaviour.

**Mathematical Calculation:** Numerical calculation may be severely impaired, not only high-level information processing. For example pupils may no longer be able to count a handful of money correctly, although they may know the value of each coin separately. Pupils may have trouble understanding a simple graph or table of mathematical information, although they know what each isolated figure represents.

**Cognitive Fatigue:** Cognitive fatigue means inability to concentrate for normal periods of time. The pupil's ability to focus on mental tasks wanes, with serious implications both for working to the expected timetable, and for coping with examination schedules. Continuing work when cognitive fatigue sets in generally aggravates symptoms. The brain becomes unable to perform, and if the pupil then makes a great effort to continue mental work, this often results in physical deterioration a day or so later. If cognitive difficulties are not fully appreciated, school staff can unintentionally add to a pupil's distress by implying that they are lazy, or not paying attention. (MacIntyre, 1999)

## **Sleep Disorder**

Because the sleep disorder that is associated with ME/CFS and/or FMS can be one of the most devastating and disabling symptoms in young people with ME/CFS, we make special note of it here. It is not known to what extent and how this sleep disorder interacts or even causes some of the neurocognitive problems in this illness. Teachers need to know that this sleep disorder can cause major problems for young people, making it difficult for them to get to school and often contributing to feelings of desperation in themselves and in their parents. Families need to see addressing the sleep disorder as an urgent medical priority. However, the sleep disorder in ME/CFS can be very difficult to treat.

## **Secondary Cognitive Problems**

Teachers and educational psychologists are well aware of the rapid growth and development of the brain in childhood. ME researcher Dr. Elizabeth Dowsett discusses the potential long-term implications of brain dysfunction for children's mental development and educational outcomes.

She states: "A good memory is the corner stone of the human mind and deprivation of special educational provision in their most formative years is the greatest disability inflicted on young people with ME/CFS."

It is important to realise that not every young person will have each of the neurocognitive, learning and secondary problems described above. And some may have other problems not listed above. Parent reports to the National ME/FMS Action Network suggest that some young people will have problems with auditory processing difficulties and difficulties with memorisation and retrieval. Others have reported appetite disturbances sometimes mistaken for anorexia nervosa. People have used the term 'obsessive' to describe some youngster's single-minded interests. There is often a great deal of confusion about what is and what is not a symptom of ME/CFS and/or FMS. The assessment of cognitive problems is discussed further in the following chapter.

### **Emotional Symptoms**

In any person, well or ill, feeling states, or emotions, do not have only psychological origins. They are affected by brain function, too (and vice versa). Several researchers have postulated that anxiety-like and panic-like symptoms in ME/CFS do not arise from psychological disturbance but from the physical disruptions in the brain. This notion has been proposed for some time. In "What is ME/CFS?", Dr. Byron Hyde, extracted symptoms in children from the work of Wallis and Behan and noted that, among the many other symptoms, children often had "weeping tendencies, and [these symptoms] appeared early [in the course of the illness]. Nearly all affected children are first diagnosed as hysterical, depression or 'parental over-involvement'....Temper tantrums were frequent in young children. In older children unsociability, lack of attention and effort on return to school was frequent. If behaviour was checked, children tended to weep".

In a discussion entitled "The Psychosocial and Psychiatric Aspects of CFIDS", child psychiatrist, Dr. Alan Gurwitt (1995) states that "among the major primary biologically caused symptoms are acute and chronic anxiety episodes and panic attacks, emotional lability, sleep problems, and depression... Many of these biologically-based problems may fluctuate in severity often in conjunction with other physical symptoms".

If teachers reading this have difficulty understanding the concept of "biologically caused" emotional symptoms, they might think about what happens if a healthy child drinks too much coca-cola. The child may become "jumpy" or "hyper" from the caffeine in the drink. Just as there's no need to look for problems at home to explain this behaviour, without concrete evidence, there is no valid reason (without evidence) to blame external factors or the child's psychological state for the emotional swings and outbursts that can accompany ME/CFS. Of course, these biological fluctuations in mood may impair learning to some degree and may also have adverse consequences socially and in the family. Then these primary emotional symptoms may lead to secondary ones.

### **Secondary Emotional Problems**

The authors of the British report "Childhood ME" comment:

A study in the US evaluated the symptoms, severity, social support and ways of coping in 69 adolescents with ME/CFS. The results showed nothing to suggest that ME is primarily a psychiatric or psychosomatic illness, nor that adaptive coping styles reduced the severity of the illness. (Bell,1996). However exposure to stress does

increase the severity of the symptoms. The existence or incidence of co-morbid psychiatric illness in ME patients under 20 years of age has not yet been formally established, but is probably present at the same incidence as in the general population.

In Chapter 1, Medical Aspects of ME/CFS/FMS, it was stated the depression is estimated to occur between 40% and 75% of children with ME/CFS and/or FMS. This risk of depression is present for children and adolescents with other chronic illnesses and is a very understandable reaction to all the losses and misery created by being so ill and so cut off from the normal activities of childhood and adolescence. In ME/CFS and/or FMS, in some cases these depressive symptoms are aspects of the brain dysfunction (Gurwitt, 1995).

MacIntyre and associates (1999) suggest that family dynamics can provide a clue about depression in these children, my view is that experiences in school may play an even larger role in this situation. This is a question calling for more research.

Teachers need to be aware of the risk of depression and suicide in all young people, including those with ME/CFS and/or FMS. Parents are often the first people to appreciate how deeply their child is suffering and if they ask you if you see the same thing, you should be honest with them. You may help save a child's life.

**Karen's** marks began declining rapidly in the tenth grade. Her teachers would not help her to catch up when she missed school due to frequent episodes of illness. We tried to be as supportive as we could at home. However, by mid-year, Karen was severely depressed and suicidal. She was very confused about her cognitive problems and emotional sensitivity and expressed her fear that she was losing her mind.

**Stuart** has had to drop so many courses such as Chemistry and computers because he missed too much class time and they were impossible to keep up on his own at home. Unfortunately he has been much worse in the past 1 1/2 years with CFS. He finds it hard to concentrate at all and is sick so often. It is very discouraging for him.

When young people with ME/CFS and/or FMS develop depression, it generally magnifies their symptoms and compounds their problems. The combination of ME/CFS and/or FMS and depression is likely to have profound effects on learning and this must be taken into account in educational settings to the extent that this is possible.

## **Stress**

Everybody experiences stress. It is very fashionable to assume that all kinds of symptoms and conditions in adults and in children are caused by stress. The term "stress" is often used loosely to imply that the "stressed" person cannot cope or does not handle problems well. It is not appropriate to make assumptions that illnesses like ME/CFS and/or FMS are stress-related disorders in that way. The effect of assumptions like this, for which there is no research evidence, is to make young and adult patients feel that they are somehow responsible for making themselves sick. Then it is also assumed that they can "pull up their socks" or "change their attitudes" and get better. Imagine how you would feel if you had MS, lupus or severe arthritis and were given that kind of advice.

Of course, managing stress and self-management are important aspects of coping with any chronic illness. But that's a very different thing from saying, or implying, that the illnesses are

caused by personality factors or by the patient's attitude and behaviour. This is not to say that personality and behavioural factors don't influence how a young person copes with life and will the illness. This question has received very little study so far but research on the effects of child temperament and coping style in other illnesses (Carey & McDevitt, 1995) suggests that there is likely to be a relationship between such factors and coping with ME/CFS and/or FMS, too.

Behavioural factors are important aspects of any chronic illness. Children who have diabetes can manage their diet and their insulin either well or poorly and how well they manage their treatment will affect their symptoms. This does not mean that behavioural factors are the original cause of diabetes. Behavioural factors in ME/CFS and/or FMS, currently the subject of a great deal of debate, may turn out to be less important than the underlying biological problems in perpetuating the illness. However, it is important that research on this question not be closed too soon or evidence supporting behavioural factors disregarded completely. Anything that can help young people to get better sooner and stay well is worthy of study. In research on post-polio syndrome, considered by some to be identical with ME/CFS, Type A behaviour and failure to pace oneself, are associated with poorer functioning (Creange & Bruno, 1997). van Middendorp et al. (2001) found that, although there were some indications of psychological distress in adolescents girls with CFS: "The adolescent patients with CFS seem to retain an active and positive outlook on life, which may result in a rather adequate psychological adaptation to the syndrome, but also in maintenance of the syndrome by exceeding the physical limits brought about by the CFS" (p. 7).

### **Parents' Emotions**

Parents can become very sad in the face of their child's daily struggles. Their journey is made even harder when they are confronted with scepticism and judgement by those who do not understand these illnesses. Emilie's mother told me:

I don't feel like a particularly strong Mom. I feel confused, sad, worried, and have struggled a lot to accept this illness of Emilie's. I have done what needed to be done, though, and always tried to keep Emilie's best interests at heart.

In their book for parents, Dr. Bell and associates (1999) state: "Some parents may feel guilty about their child becoming ill, especially if they have CFIDS themselves. There is nothing any parent can do to prevent it."

Professionals need to listen and understand the roller coaster of parents' lives with an ill child and to see the anxiety and alarm exhibited by parents as normal and understandable. Families should not be blamed for the altered dynamics in their homes while doctors and others must work hard to restore feelings of hope. There is no convincing evidence that ME/CFS is caused by family problems, though when a child is ill, clearly the way parents respond will have an impact on the way young people regard the illness and view themselves. Families of young people with ME/CFS and/or FMS are often very stressed. This can sometimes cause teachers to think that the child's problems are the result of this stress. While family stress is often a cause of problems in young people, determining which came first when there is a chronic illness is very tricky. Raising ill children is always somewhat stressful; raising them when they have such misunderstood and devastating illnesses like ME/CFS and/or FMS can be extremely stressful. How this stress affects the young person is likely to be a very individual matter. Teachers can help by not blaming parents and by understanding the rollercoaster of their lives with an ill child. Your efforts to make truly workable educational plans without waiting for the bureaucratic wheels to grind will probably be the single most helpful thing you can do for the family - and the child.

## **Relapse Triggers**

However, while avoiding blaming the families or the young person for the illnesses, teachers do need to be aware of the effects of specific types of stress on young people with ME/CFS and/or FMS. Stress on young people with ME/CFS and/or FMS usually comes from being pressured to become more active, return to school, exert mental effort and participate in physical education.

If return to school occurs too early, or is not managed very gradually, together with [removal of] requirements for Physical Education, severe relapse can result. Cognitive deficits are also exacerbated by physical or mental over-exertion (Bell, 1995; DeLuca, 1997).

Although some young people push themselves, these pressures to "do more" nearly always come from people who are not in a position to judge the true effects of their advice. The most problematic effect is what patients call a "crash". Although these can be short-lived, there are reports of some young people having serious setbacks and even irreversible damage, as a result of overexertion. (Remember, a "crash" can be delayed for up to 3 days after the exertion.)

## **Will These Children Get Better?**

Teachers and families need to be aware of the big picture. This is where statistical studies and the clinical experience of doctors who have helped thousands of people with ME/CFS and/or FMS can be so helpful. The British report, "Childhood ME" draws some cautious conclusions about prognosis in children and adolescents. Since they wrote this report, there has been a little more published research on recovery, which has had similar findings. Rangel et al. (2000) considered that most children recover although some children had a very severe course. Bell et al. (2001) reported that twenty percent of participants remain ill with significant symptoms and activity limitation 13 years after illness onset. However, Speight et al. (2001) reported a much higher level of recovery at the Sydney 2001 Conference:

- Full recovery was seen in 15 cases (31%) (5 mild, 8 moderate and 2 severe)
- Mean duration of illness in this group was 5.1 years
- Significant improvement (change to a less severe category) was seen in 7 cases (14%)
- Twenty-seven cases (55%) were static at the time of follow-up, of whom 7 were still in the severe category

The authors of "Childhood ME" state: "it is significant that some children in each group continue to experience significant fatigue and disability. It is possible that these children who do not improve represent a subset of paediatric CFS (ME) patients, potentially having a more severe form of the illness or differing in other important traits". Those experience persistent disability tend to have symptoms that are more severe from the beginning and which result in severe activity limitation. They tend to have more severe neurologic symptoms "including myoclonus, paraesthesia, and seizure-like episodes." (Jordan et al, 1998, cited in MacIntyre, 1999) They add that, because children with ME/CFS typically go in and out of periods of wellness and relapse, "a child who appears to be recovering needs to be careful about exercise for at least a year". (MacIntyre, 1999) It seems that younger children recover more fully than adults, but younger children with a gradual onset may have problems over a longer period of time.

## **How Do You Define Recovery?**

A lot, of course, depends on how you define "recovery". This is what the authors of the British report, "Childhood ME" had to say on this topic:

'Recovery' means the achievement of an acceptable life style in comparison with a 'normal' adult population. There are different degrees of recovery from a return to a tolerable energy level and lifestyle, to complete recovery to the pre-illness activity potential. It is possible that many people with ME/CFS who 'recover' have in fact adapted to a lower energy level and modification of lifestyle. What is unknown is what quality of life would have been achievable had the person not become ill in the first place. We remain very guarded as to individual prognosis. David Bell's study, presented in San Francisco, concluded that there were no clear pointers to the predicted course of the illness in any individual child. (Bell 1996).

Even if the word "recovery" is not completely accurate, there is no question that the vast majority of young people with ME/CFS and/or FMS experience remarkable improvement.

**Stuart**, reported 2 years ago by his mother:

Unfortunately Stuart is in a terrible crash right now and hasn't been able to attend school or do any work for 2 weeks. He is only taking 2 subjects but we are afraid he might have to give them up. It is very frustrating and discouraging. It breaks my heart. Today I was at the school to drive my other son somewhere and I saw all these young people so energetic and happy and healthy enjoying the beautiful spring day. And he can't get out of the house. School is probably harmful to his health - as he says he can hardly make it through the corridors. But not to go would be worse, we think. He would feel totally cut off.

**Stuart**, now, reported by his mother:

I'm happy to Stuart finished high school and has this semester off. He was supposed to have sinus surgery soon but that was postponed so he could see someone more specialised who has booked him for surgery two months from now. This has given him an opportunity to try a part-time job for the first time and although he still gets tired, 4 hour shifts at a college lunch room well for him since the time is 4:00 to 8:00 pm. It is wonderful not to have the stress of schoolwork hanging over him all the time.

Although the figures on recovery mean that some young people will remain significantly disabled, it is not helpful to surround them with an atmosphere of pessimism. We do not know what science may bring in the way of effective treatments tomorrow, next week or next year. We owe it to youth to be hopeful but mindful of the cost of their current situation. This brings us to the question of the quality of life.

### **Quality of Life**

Both acutely and less severely ill children and adolescents with ME/CFS experience time away from school, loss of contact with peers, and often daily bouts of intractable pain and exhausting flu-like feelings. They may not have sufficient attention and energy to tolerate being read to, to watch television or otherwise distract themselves from their plight. What is the quality of life of these young people? Nobody could explain what it is like to live with this illness better than the person herself. Su Lin's mother sent us this letter that her daughter wrote to a classmate who was doing a school project on the illness:

Dear Lisa:

How has CFS affected my life? The first thing that comes to mind is the fact that at age 16 (almost 17) I need the help of my mother to send you this letter. I was a straight A student but since my illness my cognitive abilities have been extremely challenged. I can no longer read a novel or write a letter or an essay. I have problems understanding things that used to come easily and can't remember things like I used to. For the past 5 years I have not been able to do grade level schoolwork. I have a homebound teacher who comes weekly but it is a struggle just to do very minimal work. Since the time I was 3 years old I was sure I would be heading for university and a career as a doctor. Now, I wonder when I will be able to complete high school, read a novel once again or write you a letter without the aid of someone else.

So, much of my life is now dependent on other people. I was always very independent at a young age but now I require help with so many things. At times I need help with such simple things as drying my hair or dressing. I need someone to prepare my meals (I used to love to cook), do my laundry, make my bed, help me with projects. I know many people think this is what most teenagers want. Help with everything. But, it is not true - when independence is taken away from you because your body won't co-operate it is very difficult.

I was a dancer, a gymnast, a swimmer. I was on the basketball team at school and very involved in school activities. I now require the aid of a wheelchair for outings and have difficulties walking around the yard. Any exercise (something I loved) is now followed by extreme exhaustion that can put me to bed for days or even weeks. I still attempt gentle exercise but it is always followed by pain, exhaustion, and a host of other symptoms. There are days when I can't seem to keep my balance, days with severe nausea, dizziness, terrible migraine headaches.....and there is always extreme exhaustion even after rest. Always there seems to be a dependence on my family. I am doing better than years ago when I was virtually paralysed. I could not bathe, feed or toilet myself - I could not turn over in my bed without help.... I still have bad days but I also have better days.

My life and my family's life has changed - our lifestyle has changed to adapt to my needs. Everything is dependent on how I am feeling, how much rest I will need. I developed severe chemical sensitivities as a result of this illness. Any scented products make me very ill. I am not able to be in public places such as shopping malls, movie theatres, schools, public buildings - even hospitals can make me very sick. Friends can not visit if they wear perfume or scented products because I am so sensitive - this includes such things as hairsprays, shampoos, conditioners, deodorants, laundry detergent, hand creams..... it is very hard to avoid these things outside our home. Many "friends" and "relatives" find it difficult to visit under these circumstances and thus, over the years contact has faded away.

I think this is the most difficult thing about this illness. The isolation. I want to be a teenager at school, I want to be involved in school activities, sport activities, having fun with my peers... I would love to be complaining about a certain teacher or the amount of homework due for tomorrow. I do have a few friends who have stuck by me. For that I am very thankful. They visit, we talk on the phone but it is hard to listen to all the teenage activities I am missing. I dream of roller-blading, hang gliding, water skiing and the like but for now I am concentrating on the day when I

will not have to use my wheelchair. For the day when I can once again read a novel, the day I can drive a car, hop on the bus with my friends, the day I too can shop at the mall... for now, I will be thankful for the friends I have and the improvements I have made.

This illness would be much easier to tolerate if medical care was easy to find. Unfortunately, there are many doctors who don't recognise this illness as being a serious one. Many doctors offer "treatment plans" that make things far worse.....many doctors don't listen. We have been fortunate to find some doctors who really care, who do realise this is a very disabling illness, who really try to offer help. Unfortunately, we had to go through many negative experiences before finding some positive ones. One doctor once told me I was a pioneer and that in time all doctors would understand more about the illness....for now, it was up to people with CFS to help educate the doctors and the public about this illness. This can be very difficult to do when you are constantly challenged by fatigue, weakness, pain, dizziness, headaches, sleep problems, etc., etc., etc., but the same doctor told me his best advise to me was patience, patience , patience and more patience. I have had to force myself to learn patience in my every everyday life in order to deal with this illness.

Having an illness does make you realise the important things in life. You never take anything for granted - there is beauty in all the little things that surround you. It is a gift to see this but, would I trade it all for feeling well, being with my friends, attending my prom, planning for university.....a cure.....you bet I would!!!!

Lisa.....My mom and I discussed what I wanted to say, she then wrote the sentences and we discussed and re-wrote.....as we were re-reading it my mom was in tears - its hard not to get emotional when you think of what we have been through. Better Days Ahead!!!!

Love, Su Lin

### **Follow-Up**

We had the opportunity to follow up Erin, Karen, Emilie, Michael, and Stuart.

**Emilie**, reported by her mother:

In grade 12 she had worsened even more but still tried to take one biology class. I ended up reading her text book to her every night and writing down her answers to her homework questions as she dictated them to me. She missed a lot but we had set up an arrangement with the teacher to tape classes missed for her. We bought a tiny recorder that he could put in his shirt pocket and this worked rather well since Emilie is an auditory learner. However, her head was so foggy and she was just getting worse and worse so she quit in early November. This has been the last schooling she has attempted for over two years. She cannot read and has trouble taking all in that is spoken to her now. Concentration is a big problem and it has been only getting worse as time goes on.

**Erin**, in her own words:

I finally gave up school last year when I failed drama because I was not there for the required 110 hours but I did all the work necessary to pass the class. The teacher said I had "great potential as a drama student and could make up the hours

doing MORE work". I was just too sick and it wasn't important. I may not have the education that I'm entitled to but I've learned lots from other resources. I've used my computer, Internet, tapes, videos for the blind, correspondence, books, hands on learning, and many other sources including peers and adults.

**Karen**, reported by her mother:

Karen, 21 at the time of this writing, is now attending college full-time and doing well. Has she truly recovered? She sleeps late every weekend and catches naps as often as she can. She still has some cognitive problems, especially with short term memory. She can't concentrate on something like reading for very long, either.

Remember that Karen had only mild ME/CFS. And while she is doing far better than many young people with ME/CFS, her parents believe she is not really meeting the potential she would have had had she not been ill. On the other hand, Karen herself said she is glad she went through her illness, including her depression:

Having ME/CFS has made me stronger and I have more empathy for other people. I have more confidence in myself and I know what my goals are. It has also strengthened my religious faith.

**Michael**, reported by his father:

At this time, he is back at school part time, and has a tutor. We expect that he will go to school full-time by next September, possibly with a modified program. He was severely disabled last summer, sometimes using a wheelchair or being carried. Now, however, he is doing amazingly well, which is not uncommon for kids.

## **The Future**

How do all the losses young people with ME/CFS experience affect their overall development? Do they have big gaps in their cognitive abilities and/or general knowledge? Do they lack "street smarts"? And, are there any gains to be achieved by living through this very tough ordeal? Su Lin's courage and strength are astounding. Did you notice how she recalled her former self? This is a very painful area for adults and young people with ME/CFS and/or FMS. They are often acutely aware of who they once were and therefore who they might have become. It can be devastating to give up those dreams and hopes and set very different goals in life.

Although many have described the remarkable resiliency of this group of young people, teachers will recognise the potential developmental costs associated with this type of maturity as well as with the losses and frustration that these young people endure (MacIntyre, 1999). When teachers can help these courageous young people to replace old dreams with new hopes and achievements they are truly helping to make a lifelong, positive impact on a young person's self-worth. Teachers also know the important role that social contact and education play in nurturing growing young minds and souls. Families should not have to try to provide these without support from society and from educators. The next chapter describes how teachers can work with students and their parents to develop truly workable educational plans for these young people at risk.

## Chapter 5

# Educational Planning and Approaches to Curriculum

by the

### TEACH-ME Task Force

Personnel who limit options for students with CFIDS/FMS because of concerns about "setting a precedent" are not truly accommodating. True accommodation reflects an honest attempt to find realistic and workable solutions on a case-by-case basis. -- From: *Guidelines for Schools*, The National CFIDS Foundation

Appropriate education for children with ME/CFS differs considerably from that needed in other illnesses. Because of the cognitive dysfunction exacerbated by effort (lesions similar to polio are observable on MRI scan and lowered blood flow to the brain occurs after mental and physical activity) together with physical deterioration following too ambitious re-integration to school, there is a need for long-term special educational provision. -- Jane Colby, *Focusing on Children*.

#### **The Scope of this Sourcebook**

In this chapter, a group of Canadian teachers with personal experience of ME/CFS and FMS offer some suggestions to their colleagues in a spirit of creativity and collaboration. We have not attempted to be comprehensive and we acknowledge that the strategies have not been researched. We hope that teachers will find that the suggestions spark new ideas and new strategies. We have confidence that, when working in partnership with the parent and child, teachers will make school and other educational venues welcoming and profitable for these vulnerable young people.

#### **The Principles behind the Suggestions in This Sourcebook**

Whether they are making accommodations on the basis of a formal IEP or in a more informal way, teachers will often be asked to modify the way that they normally teach. It is difficult for anyone to be asked to change what they are accustomed to doing, and particularly so for teachers who may have over thirty young people in their classrooms or teach over ninety students in a day. One of the purposes of this Sourcebook is to help teachers to feel more creative, more enthusiastic, and less overwhelmed, by the special requests made of them on behalf of children and adolescents with ME/CFS and/or FMS.

#### **Impact of ME/CFS and/or FMS on Attendance**

ME/CFS and FMS can have a huge impact on a young person's ability to attend school regularly and perform consistently. Speight and associates (2001) reported that in their British study, "school loss was considerable, with a total of 89 academic years being lost out of a possible 220 years, and the average school loss per child was 1.8 years". The author states:

The educational impact of the illness most closely correlated with illness outcome. Fourteen participants (40%) missed "little or no school", 8 (22.9%) missed from 1 to

6 months, 3 (8.6%) missed 6 to 12 months, 2 (5.7%) missed 1 to 2 years of school, and 8 (22%) missed >2 years of school (p. 996).

They also report that, "in general, the social effect paralleled the perceived illness outcome" (p. 996).

Gray and associates (2001) found that adolescents with CFS had significant functional disability as measured by time lost from school. Their subjects missed an average of 72 days of school per year, in contrast with 11.4 days lost by young people with depression, and 7.5 days per year by young people with juvenile rheumatoid arthritis. Interestingly, even before the "onset" of CFS, their subjects missed more school than the other groups, raising questions about risk factors, and about the possibility that there may be the emergence of early and unrecognised symptoms in cases of both acute and insidious onset.

In "Does ME Cluster in Schools", Dowsett reported that, in their study of long-term sickness absence due to ME/CFS in UK schools, only 29% of respondents under the age of 25 were in full time education, training or work, while 34% were totally excluded from all three. The remaining 37% were making various compromises, few of which could be considered satisfactory. Dr. Dowsett writes: "An enormous loss of independence and self-esteem was reported, with additional grief at the general disbelief expressed not only by the press and by various professionals but at the loss of support even from friends, colleagues, family members and those in a previously loving relationship." In Bell and associate's (2001) follow-up study, absence from school was correlated with more severe symptoms and reports of poorer social impact.

The loss of time from school, and from all the other activities that are associated with school, along with social misunderstanding and stigmatization, are of very grave concern to doctors, parents, teachers and the young people themselves. And yet the loss of time in school has no simple solution. To see why this is so, we need to revisit the symptoms listed in the previous chapter and discuss their impact on education.

1. **Fatigue/Asthenia.** The asthenia of ME/CFS and/or FMS is a primary problem for a young person in an educational setting. The typical school day is six hours long, and this does not take into account the time and energy used getting prepared in the morning, traveling, and returning at the end of the day. Schools require participation in physical education, often three times a week. If looked at in terms of energy demands, the life of a school-age child or adolescent is highly demanding. (Bell et al., 1999).

Physical and mental demands often do not end with the end of the school day. It is a serious concern when school districts or teachers dictate that homework is compulsory and thereby interferes with appropriate individual educational planning for children with ME/CFS and/or FMS. Projects to be completed at home (after a day or part day at school or even on weekends) can create enormous difficulties, too.

2. **Severe malaise (feeling 'poisoned'), particularly following physical or mental exertion.** Feelings of illness are difficult to ignore and 'push through', whether you are an adult or a young person. The malaise that accompanies ME/CFS and/or FMS is often not relieved with medication or short rest breaks and may worsen over the course of a day.

3. **Persistent headache, not responding to painkillers.** The headaches that accompany ME/CFS and/or FMS make it difficult to concentrate, tolerate bright light and noise, and to 'think straight'.
4. **Disturbance of normal sleep pattern. Hyper-somnolence is commonest initially, often progressing to sleep reversal, or else insomnia.** As was discussed in the previous chapter, sleep disorders can cause major problems for young people, making it difficult for them to get to school and often contributing to feelings of desperation in themselves and in their parents. Although this topic needs more research, sleep problems may be major contributors to some of the cognitive problems.
5. **Neurocognitive disturbance is invariably present (e.g. loss of attention, concentration, and short-term memory, forgetting names, inability to understand a written paragraph).** These problems were described in the previous chapter. The demands of education in terms of cognitive function are very great; nobody should underestimate the challenges that these present to any student. Consider the extra difficulty when they are present in a young person who is also fatigable and who may have other physical symptoms.
6. **Visual disturbance (eye pain, blurring, especially when reading).** Common sense tells us that visual disturbance is handicapping in classroom requiring reading the blackboard, reading texts, writing and working on computers.
7. **Sensitivity to sound and/or light.** Contemporary schools are bright and very noisy places. Playground, hallway and even classroom activity can be truly overwhelming to the young person with ME/CFS and/or FMS. Concerts and other school events may be impossible.
8. **Recurrent sore throat and/or swollen glands (misleading in children, who develop them with every infection. Prolonged adenopathy may need investigation to exclude TB or malignancy).** These symptoms contribute to the feelings of illness and malaise. They may also contribute to frequent time away from school as parents and physicians attempt to determine whether there is a new infection present that needs treatment. Some youngsters with ME/CFS and/or FMS do indeed have recurrent infections.
9. **Muscle or joint pain, especially of lower back and lower limbs.** Schools have stairways and hallways, hard chairs and very few places where a young person can rest his or her aching limbs. There are books to be carried and buses to catch.

Miryam Williamson (1996) is an author who had FMS as a child. She recalls:

FM for me as a child consisted of intermittent severe diarrhea, difficulty controlling my bladder, shooting pains in my legs, deep aches in my calf muscles that felt as though my marrow was burning, frequent severe headaches, lack of stamina, and insomnia. Some of my earliest school memories are of teachers joining in with my classmates to taunt me because I wasn't always sure where my feet were. Needless to say, I was never the first chosen for any team game.

Children who squirm and fidget in class may be trying to keep themselves from falling asleep. They may also find it painful to sit in one place for long periods of time. Some symptoms of FM may manifest themselves in the classroom as Attention Deficit Disorder (ADD). Not all children with ADD are hyperactive, as was once thought. There is a form known as 'quiet-ADD'. Some paediatricians say this may be an early symptom of fibromyalgia in some children. A sharp paediatrician can tell the difference between ADD and FM by performing a tender point examination.

10. **Nausea, abdominal pain, loss of appetite.** Young people who have a low appetite may compromise their energy by not eating adequately; abdominal pain is so severe that functioning is impossible. Many young people with ME/CFS and/or FMS have allergies and food sensitivities and teachers are aware of the various difficulties that these can cause in schools.
11. **Balance disturbance, or dizziness on sudden change of position.** Schools often require rapid movement from classroom to classroom. These demands can feel overwhelming to the young person with dizziness as a primary symptom.
12. **Altered subjective temperature regulation (inappropriate sensations of fevers or chills, night sweats), and maybe objective reversal of sleep/temperature rhythms.** As with sore glands and sore throats, these symptoms contribute to absences from school, diagnostic confusion and visits to medical offices and laboratories.
13. **Facial pallor, especially with the onset of severe fatigue (Ramsay 1986).** Pallor can be the cause of taunting from peers. One youth with ME/CFS and/or FMS was so humiliated by such teasing that he resorted to applying artificial tanning solution to his skin, causing even greater teasing by his peers.
14. **Altered skin sensitivity, paraesthesiae (numbness, tingling), transient rash.** Any type of discomfort makes it more difficult to concentrate and skin can be sensitive to the temperatures of classrooms.
15. **Mood changes (irritability, depression, anger and frustration) that are out of character.** Not all young people have marked difficulties with emotional lability in ME/CFS and/or FMS but some do. Sadly, these emotional symptoms may cause teachers, peers, and sometimes parents to label the young person as difficult, depressed, unmotivated, unstable, or self-centred. The social dynamics related to these symptoms remain unstudied in juvenile ME/CFS and FMS but are likely to be quite significant for some children. How emotional symptoms interact with cognitive problems has not been studied in children with ME/CFS and/or FMS, but some adult patients report that the more mental effort they exert the more labile they become.

### **Very Severe Forms of ME/CFS**

The plight of this severely affected group of children is urgent. These young people cannot attend school. Their education is a very difficult problem but this does not mean that they should withdraw into total invisibility. Teachers need to serve as advocates for these children and their families, perhaps especially when social services gets involved and attempt to enforce attendance (MacIntyre, 1999).

## **Other Symptoms of ME/CFS and/or FMS**

Remember that ME/CFS and/or FMS also involve problems with most systems in the body. In addition, the student may be on medications that have side effects for any of the above. Multiple chemical sensitivities can be a very serious problem, as Su Lin's mother reported:

I have a 17-year-old daughter who has missed 5 years of school.... She was totally bedridden for a couple years and is still homebound. She is gradually doing better, however her cognitive abilities remain very challenged. Once an A student she cannot read or write more than what you would see in a greeting card. She has had a homebound teacher throughout high school. However, she has not been able to keep up with any type of grade level studies. In a few weeks her peers will be graduating - Su Lin does not have her Grade 8. We have continued with homebound schooling mainly so she feels a connection to the school but we have concentrated on healing, not schooling. Su Lin also developed severe multiple chemical sensitivity which has been an extreme challenge.

Children with ME/CFS and/or FMS often exhibit sensitivity to odours and their symptoms can be exacerbated by exposure to everyday chemicals, such as perfume, paint, varnish, household cleaning agents and cigarette smoke (MacIntyre, 1999). Teachers will have to examine their classrooms for the presence of any substances reported by the team to cause problem for an individual child. However, parents have reported that it has sometimes been impossible to obtain a truly 'trigger-free' environment for their children.

## **Determining Reasonable Accommodations - An Individualized Approach**

The relationship between a young person's ability to resume activities and to sustain a consistent level of activity on a daily basis has been considered a key factor in making educational accommodations (Bell et al., 1999). It is well accepted that attending school is in itself an important goal for all young people and good school attendance tends to correlate with psychological adjustment. However, not all researcher/clinicians agree with this emphasis on school attendance in the case of ME/CFS and/or FMS. Our view is that young people with ME/CFS and/or FMS are entitled to an education and the other benefits that come from attending school; however, it must be provided to them in a way that is not hazardous to their health. The difficulty lies in our inability to measure or predict a healthy activity level in a young person with ME/CFS and/or FMS in a relatively easy, standardised way. We hope that research will soon provide solid information that will guide us all on this question. However, it is possible that there will never be a quick and easy determination of how much activity to encourage or discourage in young people with these complex illnesses.

In "Focussing on Children", Colby has written:

How should we educate these young people? Should we simply return them to school as soon as they can drag their bodies there, no matter how detrimental it is to their educational achievements, no matter how ill they feel and no matter how much we expose them to new infections and provoke relapse? ...In the UK, even where home tuition is initially provided, there is often great pressure on the families somehow to wave a magic wand, get their children better, and into school. No-one has the power to do that. The disease runs its course, relapsing and remitting, and until it has stabilised and school attendance may begin to be productive rather than destructive, the cases who do win long-term home tuition show that excellent exam results are obtainable if the energy reserves of the body are preserved so that the

mind can function. The debate should not be about whether children should be put back into schools or not, but about what education is for in the first place. If it is to educate, to enable good qualifications to be obtained, then the educational result is more important than in what environment it is achieved. The environment is secondary.

Equipping schools with knowledge about the ME/CFS and/or FMS, coupled with ensuring that there is commitment to the rights of young people with disabling chronic illnesses, are the only ways to ensure that young people with ME/CFS and/or FM will receive the education to which they are entitled. In Canada, reports coming to the National ME/FM Action Network suggest that there continues to be pressure placed on families to return their children to school as quickly as possible. Although we urge teachers and other school personnel to exercise due caution here, the reality is that most educational accommodations will hinge on the young person's ability to resume and sustain a consistent level of activity. Thus, determining reasonable expectations of activity for the young person with ME/CFS and/or FMS is a necessary, though profoundly challenging task for the physician, the family, the teacher and the young person who is ill. It nearly always comes from a difficult trial-and-error process, except where there is a medical opinion that even a trial period is dangerous.

The question of restricting or encouraging activity in young people with ME/CFS and/or FMS is a medical, not an educational, issue. Children with ME/CFS and/or FMS are all individuals and have unique medical and social histories and different family contexts. There will be some young people who need to try to do more and see how it goes and there will be some who need to do less. There will be many who will need to resume activities much more slowly than they, and others, realise. There will also be a number who need to engage in periods of activity and rest in a more balanced way. An individualised, medically-based approach to resuming or limiting activity is absolutely essential.

Dr. Bell and associates' approach to resuming activity, including the return to school, is laid out in "A Parent's Guide to CFIDS" (Bell et al., 1999). They state that a youngster should be able to spend up to three hours in a public place such as a shopping mall without experiencing symptoms in the following 12 to 48 hours, before they can really function in school. Knowing more about the illnesses will help prevent teachers and parents from encouraging educational plans that stress a young person into relapse or that jeopardise their wellbeing or the possibility of recovery by restricting them too much. Reading general material provides an important overview of the issues. However, when it comes to an individual young person, care must be taken not to overlook the child's individual presentation and course of the illness, which may not be 'typical'.

### **ME/CFS and/or FMS Are Unique**

Energy expenditure in ME/CFS and/or FMS has an impact on all of the symptoms, including the cognitive problems. Although the physical disability may require the use of a wheelchair, and the sensory sensitivities a special environment, it is the need for pacing in various forms that is the major thrust behind the request for educational accommodations. It is this need which is not the same as that in other illnesses, even fatiguing ones such as juvenile rheumatoid arthritis. It is this need which schools currently have the most difficulty accommodating. However, by its endorsement of the UN Convention on the Rights of the Child, Canada has acknowledged the rights of all Canadian children with disabilities to an education. Therefore, accommodations must be made for children and adolescents with ME/CFS and/or FMS, and school policies and practices may well need to be reformed so that they can be implemented in

the most expeditious way and so that they truly meet the needs of young people with these complex illnesses.

## **Pacing**

As we move into more specific educational accommodations, it is important to keep in mind the general approach to illness management in ME/CFS and/or FMS which must be honoured, not violated, by educational plans. The foremost concept is pacing. Pacing is a concept that is used a great deal in rehabilitation and yet it is often misunderstood in its application to ME/CFS and/or FMS. It does not mean advising young people to push themselves until they "crash". In "Pacing for ME and CFS: The Facts", Dr. Ellen Goudsmitt, ME/CFS researcher states:

... The aim of pacing is to remain as active as possible but to avoid the relapses resulting from over-exertion. As you improve (whether as a result of medication, other therapies, time or luck), your boundaries will increase and you will gradually be able to do more. If people want to increase their activity levels every few days, that's fine, as long as they remain "within the limitations which the disease imposes" (Ramsay, Medical Update 1990, no. 1).

In practice, pacing means stopping an activity when you feel you have reached that point where pleasant tiredness becomes unpleasant, where arms or legs begin to feel weak, or where one starts to feel unwell or sick. Some might find it more helpful to rest at the first sign of muscle weakness, and then carry on. Dr. Ho-Yen wrote in his book, "Learn to listen to your body. It will tell you when there is a problem". And I believe that too. Pacing also means you limit activities per day, e.g. washing one day, ironing the next.

And if you are bed-bound, it means pacing yourself on the telephone and surfing the net. However, if you are tired-all-the-time and you have no energy at all, then your doctor needs to reassess you. ME is a fluctuating condition, except during the most severe of relapses.

## **Activity Limitation: Its Implications in Young People**

Teachers should not interpret the concept of pacing to mean that the young person with ME/CFS and/or FMS should be stifled or pampered. The goal is always to try to improve functioning or maintain good functioning when it has been achieved. Pacing plays a key role in both improvement and maintenance of functioning. However, it is a difficult concept for the young to implement (MacIntyre, 1999). Healthy children and adolescents are very active people, interested in the world around them, and determined to keep up with each other. Young people with ME/CFS and/or FMS who emulate their healthy peers are trying to be 'normal'. Teachers and others should never underestimate the complex psychological issues involved when any young person is trying to come to terms with the limitations imposed by a disability. Furthermore, because of the possibility of recovery, many young people with ME/CFS and/or FMS are never given license to see themselves as disabled, and some reject the diagnosis (Bell et al., 1999). It is all the more understandable that some young people will attempt to be as active as possible.

## **Self-Regulation**

Ideally an individual daily timetable should be discussed with the child and family, one which enables the sick child to live within his or her limits without increasing symptoms, and in which the activities can be repeated daily without distress. In practice this is very difficult, especially

for ill teenagers, who may rebel against imposed rules or timetables. And in addition, ME is an illness characterised by fluctuating energy and symptoms, so it may not always be feasible to follow a strict daily timetable, especially if there are unforeseen stresses (e.g. an infection or family crisis), which can lead to increased symptoms or a relapse. (MacIntyre, 1999).

Some have suggested that it is best to permit the young person with ME/CFS and/or FMS to learn by themselves what level of activity works for them, and to take responsibility for the price they may pay if they overdo it. Perhaps it is wisest to see self-regulation as a critical developmental task for all young people, but one which can be hampered by pre-illness temperament, the presence of cognitive dysfunction and emotional symptoms that are part of ME/CFS and/or FMS, illness history and demoralisation. It is also possible that rigid self-regulation may be a coping style that is not always helpful to a young person with ME/CFS and/or FMS who must adapt to the unpredictability of the illness and develop a more flexible and less of a perfectionist approach. Rangel et al. (2000) found that adolescents with CFS were scored higher on "conscientiousness, vulnerability, worthlessness and emotional lability" than normal adolescents and that stronger personality traits were associated with a poorer outcome. These findings are difficult to interpret, particularly since such 'traits' could be symptoms of the brain dysfunction that arises in the illness.

### **Teachers as Advocates**

In "CFS Children and Youth: The Human Rights Perspective", Maureen Stephenson, Research Officer for the NSW Primary Principals' Association, and researcher on ME/CFS in Australian schools comments:

To ensure CFS children and youth their entitlements in regard to human rights, the education and medical professions need to engage in productive dialogue with the CFS community to identify a way forward. The task is to develop realistic strategies to address the disharmony and disempowerment experienced by CFS children and youth and their parents. The challenge is to identify a new value system and a new consultative culture.

Teachers can serve as advocates when they help parents to find their way around 'the system'. They direct parents to the relevant authorities in Special Education departments and help them learn who is in charge of decisions affecting their child. Families and children should not have to wait while the paperwork is being handled. These children cannot afford to lose time waiting for schools to recognise that they are truly ill. While their families may have to apply for special needs categorisation, during the time that this application is in process, a child needs to feel welcomed and valued by teachers. Nothing dispels despair so well as accomplishing even a very small task every day and feeling that you are not alone and abandoned. This can be achieved by having the teacher send a daily letter to the homebound child or by making a phone call to see how the young person is doing. It can be achieved by sending home optional work or by accepting a book review or a documentary review as equivalent to an assignment with similar learning objectives. Young minds need to be engaged and prevented from shutting down.

### **Not Every Ill Young Person Can Attend 'Regular' School**

Oleske et al. (2002) state that "as many as 40% of students with CFS are too ill to attend school full-time and home tutorial services should be provided" (p. 55).

Colby (May 11, 2002) discusses the conclusions of a recent British report:

...nearly all children who are severely affected and many who are moderately affected will require home tuition, distance learning, or both. Children are commonly told to attend school for social contact, but schools these days can be pressurised, academic hothouses, where the physical and intellectual stress is unsuitable for many healthy children, let alone those with a disabling illness that affects the brain and central nervous system. Repeated relapses typically occur, undermining doctors' medical management and the child's achievement. Education can be more efficiently given via home tuition or distance learning until the child becomes strong, with social contact provided separately.

In "ME and Learning: Problems and Solutions", Colby and Jacob explain why returning to school full or part time is not a realistic expectation of all young people with ME/CFS:

The normal consideration with a child on home tuition would be to follow a regime, which will dovetail easily with the school curriculum on return, but ME typically needs a different approach. Many children are only just recovering sufficiently to attend an institution part-time by Year 11. Dowsett and Colby (1997) have shown that the prevalence of the condition peaks at age 15 and many children therefore never recover in time to return to school. They may enter [...] College with part-time attendance and/or follow various forms of distance learning. Where children return to school as soon as physically possible, they often struggle with just a few lessons per week for little academic return.

Emilie's mother describes what happened to Emilie after the diagnosis of ME/CFS.

After the boy sat on her head she became ill from then on. Same as before except worse and chronically consistent and she never has regained her health since. Three months later she went to a pediatric immunologist who diagnosed her with ME/CFS. She said she didn't know much about it but that everyone recovers in time... I was extremely frustrated and angry that I had the sole responsibility of taking care of a profoundly sick child and the medical community seemed not to have any answers at all.

**Grade 7:** It was 10 months into Emilie's illness by now and she had missed 5 complete months of school, too weak, tired, and ill to even come to the table to join her family for supper. She was too sick to put on her socks and shoes let alone walk around the block every day. It was evident that it was my responsibility to research all and everything I could get my hands on because the doctors were not going to bother. They were not worried and I seemed unable to convince them of how ill my daughter really was and how little she was capable of doing daily. We spent the winter helping her rest. She was so sick at this time that she looks back and feels she was in a coma because she remembers little. Her symptoms gradually became worse with headaches, nausea-like stomach aches, foggy head, no concentration, unable to read, unable to fall asleep and unable to stay asleep and complete and utter exhaustion....

**Grade 8:** Grade eight came and Emilie was still too ill to attend at all. Occasionally she made it to a class a week but that was pushing it. Late in the spring I brought her to an internist who I had heard was treating a lot of CFS cases. He tried her on Decadron and darn near killed her. She had an adverse reaction to the medicine and could not tolerate it.

**Grade 9:** ...In the middle of grade nine, Emilie was a tiny bit better. She could make it to one class of science a week but that was it.

**Grade 10:** Florinef enabled her to go to grade ten 3/4 of a day and it was a great year for her. After being bedridden for nearly three years it was an exhilarating experience, to say the least. In the spring of grade ten, they wanted to take her slowly off Florinef to see how she would do. Ever so slowly we decreased her dose but she did very poorly. Grade 11 she crashed again and Florinef seemed to do little even though we had increased her dose once again. She caught every thing under the sun that year and got worse with each virus she caught.

**Grade 11:** By March of grade eleven she was bedridden most of the time again. We saw Dr. N., the cardiologist, again twice in the second half of grade 11 and he tried increasing the Florinef, which didn't work and then in the summer tried Midodrine which helped Emilie a bit. At the end of August she was finally able to save up all her energy to walk about half an hour every day. Still the rest of the day was spent resting.

**Grade 12:** At this time Dr. N. referred Emilie to Dr. R. who runs a fatigue and pain disorder clinic because he didn't know what else to try since she was a CFS patient and not a fainting patient and he also felt unqualified to continue to treat her. We waited 11 months to get into to see Dr. R. whose waiting list is from 1 - 2 years long. Emilie was unable to do any grade 12 work as her cognitive problems were worsening and she could not read or concentrate at all any more. During this time when we were waiting to see Dr. R. we continued going to Emilie's family doctor for advice and help. Emilie would complain most about her foggy head and her inability to think, pay attention, etc., even though she was mostly housebound and bedridden.

Finally, we had a doctor who knew exactly how sick Emilie was and who had a plan to try to treat her. Unfortunately, what has worked for many others has not worked for Emilie. She is getting worse, still bedridden, despite Dr. R.'s wonderful care. We are now in the process of getting Emilie assessed for chiari and spinal stenosis.

Teachers reading this Sourcebook must feel very concerned about youngsters who are too ill to attend any type of school. These young people are not helped when adults create a doom-and-gloom atmosphere but planning is difficult when adults are unrealistic. Teachers can greatly help this group of young people and their families by being their advocates for very radical educational accommodations, including home- or hospital- schooling of some. When interacting with these profoundly ill children, teachers and tutors need to be very sensitive, empathic, and flexible but always optimistic that science will soon bring some answers and the hope of better health in the future. We trust that the ideas in this Sourcebook can be modified for the home- or hospital-based instruction of these young people.

In respect to children who are at home or in the hospital, teachers should note the following discussion:

Total bed rest is harmful, except for a short time during the acute phase, and leads to postural hypotension (low blood pressure) and loss of muscle strength. However most young ME patients retain muscle tone, and get up for toilet purposes even

when in a relapse. These complications can be minimised during an acute phase of illness by the application of gentle passive physiotherapy. (MacIntyre, 1999).

### **School Flexibility Is An Important Factor In Preventing A Young Person's Withdrawal**

Flexible schools are more likely to keep young people with ME/CFS and/or FMS in school for at least some of the time. In "ME and Learning: Problems and Solutions", Colby and Jacob report: "in the areas of higher provision of home tuition, children were less likely to be withdrawn from school entirely than in those offering little provision".

In "Focussing on Children", British ME researcher and educator, Jane Colby states:

The educational philosophy I have been developing, which I call status responsive education, advocates a system which is responsive both to the fluctuating Health Status of the pupil, i.e. has the ME/CFS stabilised? and the Learning Status i.e. how efficiently is the brain functioning? The overall principle is simple: targeting success. We must not continue to set up our young folk to fail, reinforcing that failure by ever more negative experiences engendered by inappropriate attendance in school.

### **Which Special Needs Categories Are Appropriate?**

On occasion, a young person with ME/CFS and/or FMS can be accommodated by a flexible teacher who makes adaptations to the curriculum and works closely with the family. However, much of the time when teachers and schools are asked to make accommodations for a young person, they are not able to provide these unless a child is categorised as "special needs". Bell and associates (1999) have discussed in some detail the quandary that families are in when deciding whether to apply for special educational services for their child. Although it is natural to hope that a child will recover enough so that such an application is not necessary, this is not likely to be the case with ME/CFS and/or FM even though great improvement is possible.

Although we have argued elsewhere that help should be given these young people even before they are diagnosed and often before they are "categorised", there is no question that young people with ME/CFS and/or FMS should be eligible for special educational services (MacIntyre, 1999). Unfortunately, parents have reported that a great deal of their time and energy is spent in trying to establish what special educational category fits the child with ME/CFS and/or FMS. Our view is that the categories are there to serve the child, not the school. Therefore whatever category or categories provide the most appropriate education for the young person should be sought. Although the most common category that is used appears to be "other health impaired" (Bell et al., 1999), it is not uncommon for a young person with ME/CFS to be categorised as "multiply disabled". If this is what provides the necessary services, it is appropriate.

### **Educational Options**

Bell and associates (1999) discussed various options that have worked in the United States, pointing out that informal arrangements, that do not require special educational classification, sometimes can work well. In terms of special educational options, they list complete home tutoring, one or two classes per day, a half day of school, full day without gym and a full day with gym to accommodate the range of severity and functioning that exists in children with ME/CFS and/or FMS. Clearly, Canadian communities vary widely and school districts differ in their sociodemographics and funding for special education. Although sometimes understanding of the impact of ME/CFS and/or FMS on education is lacking, one main difficulty for parents is

the lack of educational alternatives for their children. In the following section we describe the range of options that needs to be available for young people with ME/CFS and/or FMS.

### **Distance Education - Home Schooling**

Many school personnel assume that distance education with parents in charge of teaching will be the best arrangement for the child with a chronic illness. However, parents have reported that such arrangements do not work well for all families and all young people with ME/CFS and/or FMS. There are several issues that complicate this arrangement. The first is the sense of isolation from peers and the feelings of abandonment by schools. Such arrangements should never be prescribed by schools as a way of getting rid of a problem. Young people and their families will pick up the message that they are unwelcome and being difficult. We cannot overstate the amount of pain and anger this causes to parents and children. Another difficulty is that, as teachers well know, distance learning requires a great deal of self-discipline and self-management. While prior to becoming ill, many youth with ME/CFS and/or FMS were highly self-disciplined, difficulty with self-regulation may be part of the neurological disability, just as it is with some neurologically-based learning disorders. And for those young people who had such difficulties before they were diagnosed (and these could have been early symptoms in some), it seems unlikely they will somehow become better at these skills while ill.

Another problem with distance learning without a tutor is that parents become burdened by the role of being their child's teacher. This is difficult in many families and is likely to be much harder, if not impossible, when the parent has ME/CFS and/or FMS, too, or has other stresses. Nor can it be assumed that all families have a parent at home to perform this duty, though a number of families do have a parent take work leave when their child falls ill.

There are also models of distance learning in which an online tutor is provided to give assistance. This type of support has been reported to be quite helpful for some young people who cannot attend school. Whether they have tutor or parental support, or both, it can take a very long time for young people to cover the required courses to complete high school by distance. Having said this, there are a number of youth with ME/CFS and/or FMS who manage to complete high school in this manner. They may develop a new set of peers through email, become wonderful advocates for youth, and grow into being accomplished, strong young people who set high standards for themselves. These young people move into adulthood with wisdom and maturity, even though many are still significantly disabled. We all have much to learn from these courageous youth. Many have published remarkable papers on the Internet and we recommend that teachers read their words and communicate with the authors. (A list of youth web sites is placed at the end of the Sourcebook.)

### **Home Tutoring**

Parents have reported that home tutoring is a very workable option for the young person not well enough to attend school in a meaningful way. There is no question that there is a significant number of young people with ME/CFS and/or FMS who will benefit from instruction at home from a tutor either permanently or on a temporary basis. The goal for many of these children is an eventual return to school but, as we have noted, this is not always possible. Any administrative restriction on the length of time this service is provided fails to appreciate the complexity and challenges of the condition and may result in a disservice to the young person.

Home tutoring needs to be planned through the process of developing an Individual Education Plan so that the hours, content, pace and manner of instruction will fit the child's current health status, abilities, interests, learning style, best time for learning and physical capacities. To

institute home tutoring and not take account of individual needs and strengths is a violation of the best practice principles of special education. Parents have reported that tutoring sessions are sometimes too long, timed poorly, and that tutors are sometimes weak in special education training and in basic knowledge of certain subject areas (National CFIDS Foundation, Guidelines for Schools).

Home tutoring should start as soon as it becomes clear that in-school education cannot sufficiently meet the educational needs of the young person and a request it made. Waiting periods are seen as penalties for being sick and as a message that the young person has been abandoned by the school system. This becomes an added stress to the student and the family. Parents have reported cases of School Boards refusing to provide home instruction because of their belief that children could attend school if they tried harder or if their parents forced them. It is important for schools to remember that forcing children with ME/CFS and/or FMS can be detrimental to their health.

Often, home instruction and attending school are treated as an either/or situation. A student receiving home instruction may be afraid that if s/he attends a class party or field trip, the home instruction may be cut off. A student trying to attend one period a day at some risk to his health was told his home instruction application would not be considered because he was able to attend school. While no-one favours abusing the home instruction system, a rigid either/or attitude does little for the child's education, social development or health.

The transition back to school should also be planned with sensitivity. The return to school may not go as smoothly as hoped since the young person may not be at full strength, may have fallen behind in some areas, and may be feeling uncomfortable or insecure after having been away for some time. A home instructor may be able to help support the young person in this difficult time, by being available if relapses occur, by providing tutoring in academic areas where problems are encountered, or by advising the new teachers.

### **Part-Time Attendance in an Alternate Program**

There are many types of alternate programs in Canadian schools though not nearly enough of them. Not all parents are happy with the idea of their child attending an alternate program, nor are all youth pleased with the idea. Some parents fear that their child will be seen, and treated as, a youth with behavioural or emotional problems by such a placement and some youth fear being labelled as 'losers' by their healthy peers. It is true that, on the one hand, many alternate programs are for youth who are not fitting well in regular educational venues. However, parents of youth with ME/CFS and/or FMS, and the youth themselves, would do well to be mindful of the fact that many of these youth also have neurological disorders and are perhaps as misunderstood and as challenged as youth with ME/CFS and/or FMS. The teachers in such alternate programs are often especially trained and knowledgeable about learning that is impaired as the result of neurological problems and many have experience in working with children with chronic illness.

On the other hand, some alternate programs are fraught with tension and disciplinary issues. The atmosphere can be stressful to the more sensitive young people placed there and it is known that youth with ME/CFS and/or FM are highly sensitive to all types of stimuli and this is part of the illness. Nevertheless, it is not possible to generalise about alternate programs. They vary widely and change from year to year as the teachers change and as the specific group of students in them changes. The best practice is not to rule out such a program blindly before

investigating it but to weigh the potential costs and benefits of a specific program in a given year.

### **Part-Time Attendance in a Regular Classroom**

Many parents hope that schools will permit their child to attend their regular homeroom class or a regular secondary school program on a part-time basis. While this type of accommodation makes perfect sense to families who wish to help their child feel normal and accepted, it can be difficult for schools to permit under current policies and difficult for teachers to manage in respect to the curriculum. One of the difficulties is the concept that the young person attend "when he or she feels able to". Erratic attendance creates many complications for schools, teachers, parents and the ill child. This topic is discussed in "A Parent's Guide to CFIDS" by Dr. Bell and associates (1999). To that excellent discussion, we would add that sometimes having "erratic" attendance accepted may create important links for the child who would otherwise feel abandoned. Such accommodations should not be overruled by blind policy but discussed on a case-to-case basis with the team, with the potential costs and benefits weighed carefully.

### **Full-Time Attendance in a Regular Classroom**

Young people with ME/CFS and/or FMS who are recovering many of their former abilities may be able to return to school and attend full time. Often this is only possible if they take core courses only and use some time during the day to rest or catch up with their work. Physical education requirements may need modification, too. One of the difficulties for this group of young people is weighing their social needs, which consume energy, with their educational needs. In "A Parent's Guide to CFIDS", Dr. Bell and associates recommend allocating a percentage of time for socialising and seeing this time as essential for healthy development. Homework expectations may also need modification as a youth who has attended school for six hours may well 'crash' later in the day. As well, residual cognitive problems, as well as the physical disability, may make doing schoolwork, projects and homework challenging, even if a young person is 'physically present' in a classroom all day. The research of Dorothy Morris (2001) on young people attending post-secondary education attests to the significance of ongoing cognitive dysfunction.

### **Full-Time Attendance in an Alternate Program**

Due to the issues discussed in the previous paragraph, it may be that an alternative program can offer a full day with fewer pitfalls than a regular classroom. All the considerations about alternate programs, discussed above, apply here.

### **Transitions - A Critical Aspect of Educational Planning**

Perhaps the management of transitions from one level of school participation to a higher level is the single most important factor in ensuring that a child will succeed and not relapse into lower functioning and greater school non-attendance or withdrawal. There are many types of transitions for the young person with ME/CFS and/or FMS. They include: transitions from being homebound to attending an alternate school; transitions from alternate to regular school; changing schools and alterations to the educational plan in relation to the young person's current health. Each of these transitions requires thoughtful analysis in terms of all types of energy demands, including physical energy. Demands for activity must decrease or increase according to medical advice in consultation with the youth and family. In most of these transitions a gradual approach is necessary and this requires considerable flexibility and awareness from school personnel. MacIntyre and associates (1999) state: "Re-entry to school

should be gradual and planned with the school authorities." Unfortunately, schools are not used to the concept of gradual transitions.

### **Psychoeducational Assessment**

Most schools establish a child's eligibility for special educational services by employing psychoeducational tests. This is an area of grave concern to practitioners and parents with knowledge of ME/CFS and/or FMS. The fact is that the state of scientific knowledge about the validity of traditional assessments (such as IQ tests) in children and adolescents with ME/CFS is in its infancy. For example, an IQ score may be much lower than it should be due to the illness on cognition or to the effect of the illness on test performance. The lowered IQ score may not reflect the person's actual potential as IQ can recover over time (Bastien, 1990). On the other hand, the illness may make it very difficult for some people to reach their true potential. There is another concept in neuropsychology that is helpful in shedding light on this question. That is the concept of performance. Many people with neurological disorders, including children, cannot always perform to best of their ability because they cannot always harness what they know. They also perform inconsistently, doing better on some days than others. These problems of inadequate performance and inconsistency are often misinterpreted as problems of personality or motivation by people who do not understand neurological disability (Nader et al., 1997; Al-Adawi et al., 1998).

The interpretation of children's psychological tests is sometimes very inaccurate as a result of the lack of education of professionals about paediatric ME/CFS and/or FMS. Too many psychologists draw inappropriate inferences from test results. In "Educational Rights, Responsibilities and Options", US Advocate Michelle Banks, writes:

A mother sits across from the school psychologist while he explains the results of her daughter's special education evaluation. The psychologist holds up a piece of paper with a shakily drawn house with 3 stick figures in front. The mother is told that the poorly drawn house and the shaky stick figures could indicate that her daughter is "emotionally dependent and possibly school phobic." Hoping that it would be a positive sign, the mother points out that the stick figures are holding hands.

The psychologist explains that there is a "significant drop" of 21 points on the WISC-R intelligence test from earlier testing when her daughter was placed in gifted classes. This "profile suggests difficulties with memory, concentration, and attention." He explains that while her "ability to process information auditorially is excellent, this is in direct contrast to difficulties with math computation done in her head." The psychologist says that while testing, her daughter seemed "distractible and impulsive" which demonstrates poor planning and organisational skills.

"Are there problems at home?" the psychologist asks...

### **Special Testing Arrangements and Careful Interpretation Are Recommended**

Because of the problem of using traditional psychometric tools, Iger, who has conducted many clinical assessments on adolescents with ME/CFS, has developed her own Neurocognitive Assessment tool to make up for the deficiencies of traditional assessments. Some cautions on the topic of assessment were presented at a conference on CFS in the United States.

Cognitive testing must be conducted by a compassionate clinician who is familiar with CFIDS and/or chronic illness in general, said Robert Sedgwick, Ed.D. Dr. Sedgwick cautioned educators that fatigue confounds evaluation, thus he

recommended that doctors utilize a student's "window of opportunity," the time of day in which he or she feels best, to perform assessment.

Dr. Sedgewick suggests that the Wechsler Intelligence Scale for Children (WISC)-III can be used to assess a student's cognitive status. He states: "No hard patterns have been determined which signal CFIDS. Children with CFIDS frequently have decreases in verbal IQ and attention and concentration, yet performance IQ does not seem to be affected as much." He advised that, "in the case where no pre-illness scores are available for comparison, performance IQ may be used to estimate previous abilities on other scales". He also points out that, the presence of CFIDS does not mean that a child might not have other, pre-existing learning disabilities. If a child had previously been diagnosed with attention deficit disorder or a learning disability, this must be addressed in educational planning, too (CFIDS Association of America, 2002). We add that anecdotal reports suggest that many young people with ME/CFS were identified as gifted before they fell ill. Such information must be factored into any assessments conducted when they are ill and addressed in educational planning. The concept of "dual exceptionalities" may be helpful here:

Gifted students with disabling conditions remain a major group of underserved and understimulated youth (Cline, 1999). The focus on accommodations for their disabilities may preclude the recognition and development of their cognitive abilities. It is not unexpected, then, to find a significant discrepancy between the measured academic potential of these students and their actual performance in the classroom (Whitmore & Maker, 1985). In order for these children to reach their potential, it is imperative that their intellectual strengths be recognised and nurtured, at the same time as their disability is accommodated appropriately (Willard-Holt, 1999).

Even when children have not been identified as gifted, building on their strengths is very important. Personality factors are important, too. In "A Parent's Guide to CFIDS", Bell and associates (1999) state:

...strengths and weaknesses should not be discussed in isolation. It is important for [parents] and the evaluators to stress how your child's personal characteristics, such as motivation and persistence, may help him or her deal with the cognitive limitations.

A group is are currently compiling data on the wide array neurocognitive problems that have been reported and are attempting to ascertain the tests that can identify them (Lassesen, personal communication, April, 2002). The National ME/FM Action Network is currently conducting a preliminary survey of Canadian and international families' reports of the neurocognitive and learning problems in children with ME/CFS and/or FMS. Hopefully, these efforts will lead to larger studies by neuropsychologists familiar with these illnesses. While we are waiting for more definitive knowledge on these questions, we hope that Canadian school districts and educational psychologists will educate themselves about the problems involved in the assessment of a young person with these illnesses. Until we have the confidence that they can perform valid assessments, we have no choice but to caution teachers and parents about the limitations of psychoeducational testing.

Oleske et al. (2002) have stated: "Due to the chronicity of CFS, period measurement of quality of life should also be part of the overall clinical evaluation, such as the one proposed by Gortmacher" (p. 52).

## Psychiatric Misdiagnoses

Dr. David Bell has reported that ME/CFS and/or FMS may be misdiagnosed as attention deficit disorder (Bell, 2001).

As it is quite common for children and adolescents to develop loss of appetite secondary to ME and muscle fatigue may reduce a child's intake of food, MacIntyre (1999) reports that ME/CFS and/or FMS might be confused with *anorexia nervosa*, "especially in girls in early puberty. Anorexia nervosa is associated with a distorted body image, self induced vomiting, progressive weight loss, and frequently abuse of laxatives." They add that it is important to make the distinction early if weight loss occurs:

The most important distinguishing feature of anorexia nervosa is a distorted body image and a phobic refusal of food, coupled with a fear of getting fat. Although weight loss is commonly seen, some young people with ME gain weight, and obesity may be associated with comfort eating, lack of exercise, or possibly water retention.

*Phobic anxiety state*, particularly school phobia, is associated with panic attacks and use of the avoidance response about the most feared situation. Symptoms associated with school phobia usually resolve during weekends and school holidays. This does not occur with ME, whose symptoms may be worse at weekends and persist through school holidays, when children try even harder to tackle the activities they enjoy face on with the family. The main reason that the pupil is reluctant to go to school is because of rapid onset of fatigue, myalgia, and loss of concentration after a short time in class.

*Somatization* disorder may resemble ME in that the patient has multiple symptoms which cannot be explained by any known medical condition or by use of abusive substance or medications. In ME there is typically no secondary gain from having the symptoms, whereas this is a common feature with somatization. When evaluating the child's bodily symptoms, it is important to be aware that a child often cannot articulate about the condition, and may be stressed by the attitudes of others to the illness. In a few cases, somatization could be difficult to differentiate from ME, and there may be hidden stresses; a child can be unwilling or unable to communicate about sources of anxiety.

## Individual Education Plans (IEPs)

Special education teachers are familiar with the concept of IEPs and growing numbers of 'regular' classroom teachers are being introduced to this process as Canadian schools are becoming inclusive. As with children and adolescents with other chronic illnesses, the development of educational plans is conducted with input from the child's 'team'. The make-up of that team varies but should always include the parents. Other members of the team are teachers, tutors, teaching assistants, and sometimes physiotherapists, occupational therapists and learning specialists. In cases of ME/CFS and/or FMS there often needs to be consultation with the child's physician, although it is rare that a physician will attend a school meeting.

In spite of the fact that non-medical personnel may have strong opinions on these topics, the physical symptoms of ME/CFS and/or FMS, such as sleep disorder, pain and seizures clearly fall within the medical domain. Any educational ramifications of these problems are generally, and appropriately, brought to school by the parents in consultation with their child's physician. Direct contact between physicians and schools can occasionally be necessary, but generally

speaking such communication can create a sense of distrust on the part of parents. Except where required by law, such contact should never be made without the family's permission or without the family's presence.

Some symptoms, such as pain, may be managed better when a child or adolescent receives specialised help from a clinical psychologist or psychiatrist with knowledge of ME/CFS and/or FMS. It is therefore occasionally appropriate for such professionals to be involved with a child and family and for school consultation to be provided by these professionals, too.

### **Involve the Student in Planning**

All of this professional and parental input does not mean that the child or adolescent is not involved in educational planning. On the contrary, the authors of the UK report, "Childhood ME", point out the importance of involving the young person, especially adolescents, in making decisions (MacIntyre, 1999). Even given constraints on changing the content of the curriculum, teachers can negotiate learning activities very successfully with the young person with ME/CFS and/or FMS.

### **The Teacher-Student Relationship**

The teacher plays a critical role in forming a strong relationship with the ill student. This relationship cannot be positive if it is based on scepticism and distrust. As Hilary Tandy, Education Advisor for the Association of Youth with ME in Britain says, in "Information for Teachers":

The most important thing to young people with ME is to be believed. All too often they have had to deal with professionals who are dismissive and uninformed. This can lead to the setting of unsuitable and unrealistic goals. By believing the student and listening to the whole family, you will become an effective member of the team responsible for the care and rehabilitation of a young person. You will earn their trust.

Believing what a young person says about the experience and the symptoms of the illness does not require that teachers lower their standards or permit unacceptable behaviour. On the contrary, good teachers know that empathy coupled with appropriate limit-setting and high expectations are powerful ways of letting a young person know that they are valued and respected. Teachers who emphasise a young person's strengths and who see the person behind the illness can have a positive, lifelong impact.

Since it is important to have an idea what the student with ME/CFS and/or FMS can do without provoking a relapse, ask the student and parent, and perhaps the youngster's physician, for guidance. You may wish to ask the following: For how long can s/he usually walk? For how long can s/he usually sit? For how long can s/he usually read? For how long can s/he usually write or draw? For how long can s/he usually talk? How much can s/he usually lift? Warning: Do not perform a physical assessment of the student's abilities yourself. Obtain pertinent medical information, ask and observe. You will gather much useful information by observing the indicators listed above. Keep in mind that an activity that depletes the energy reserves will reduce the student's ability to perform the usual tasks. This, along with delayed reaction and the interaction of symptoms, is what makes the illness so confusing.

## **Physical Demands on the Homebound Student**

The problem of physical demands is not usually an issue for the homebound student, although the requirement of physical education must often still be addressed. However, school personnel must remember to keep in mind these physical limitations when they send work home, advise tutors, request meetings in the school from time to time, and when they participate in planning various transitions.

The National CFIDS Foundation (1998) makes the following comments about tutoring:

Tutoring should be scheduled for that hour or hours during which the child is generally most functional. This time may not be within the normal school day. Often the person with CFIDS/FMS is unable to do anything cognitive until the later part of the day. Ideally, the tutor would be very flexible and able to delay or advance the scheduled time of instruction.

Having the lesson plan available for a month at a time enables the student and tutor to work at their own speed. Likewise, it is strongly recommended the tutor make the plans available to the student, for the week/month. There may be times when the student is too ill to be tutored at a scheduled time, but able to work later. Without any idea of the material to be covered, the student waits until the next session. If the plan is known, materials might be able to be reviewed independently.

Given the physical, neurological and cognitive problems one experiences with CFIDS/FMS, it is recommended the tutor be certified in special education.

The tutor must be competent in his or her field of study. Reports abound of the child with limited energy having to reassure the tutor or help the tutor with the subject matter.

Often the homebound student will be unable to be tutored due to additional illness, medication reaction, relapse, medical visits, and so forth. It is important that the education plan engage the tutor with this in mind. Continuity of educational services should not be compromised because the child is too ill to receive services, the tutor quits because s/he is unable to be paid, and/or the sick child waits three months for another tutor to be found.

## **Physical Demands of Attending a School**

In order to make the appropriate adjustments to the young person's activity limitations, teachers may need to stop and reflect on what they take for granted - that all young people have boundless energy and, in fact, need to "burn it off". Attending school all day leaves healthy youngsters with plenty of energy for sports and recreation later. This is not the case for youngsters with ME/CFS and/or FMS. Consider the demands upon physical energy in attending school. Many secondary school students must move from classroom to classroom and often from building to building throughout the day. In younger children, it may be the playground and socialising which make the greatest physical demands. For some youngsters with milder ME/CFS and/or FMS this 'normal' level activity may be beneficial and may constitute the appropriate amount of exercise to maintain muscle strength. For some youngsters at the more severe end of the spectrum, the use of a wheelchair, provided that elevators and ramps are available, solves some of the problems. Colby (May 11, 2002) comments on a report on ME/CFS, published on Jan 11, 2002, by the Department of Health, in the United Kingdom. She

refers to "huge steps made in recommendations for children with these disorders: The report is unequivocal: "wheel-chairs can increase independence . . ." and "the notion of 'once in a wheelchair, never out' is prejudicial". However, it must be remembered that the use of a wheelchair, in itself, does not completely solve the problem of fatigue or other symptoms. As Colby and Jacob point out, in "ME and Learning Problems":

People with ME use a far higher proportion of energy for what is called "resting strength" than others. This is the energy expended merely to sit, digest, and carry out normal bodily functions. Experiments show that many have reduced volume of oxygen uptake. This is a measure of aerobic fitness or how efficiently the body utilises oxygen. This reduced uptake is equivalent to someone with emphysema or a 70 year old with a heart condition. It is thought to be linked to a mitochondrial dysfunction. (Behan et al., 1991) The mitochondria are the "cell batteries" from which our muscles derive energy.

### **Physical Education Requirements**

The requirement of physical education in the narrow sense of involving activities in exercise and sports must often be adapted, as with any other aspect of the curriculum, to the child's current state of disability. Although many adults may feel that more activity will benefit a youngster, in the case of ME/CFS and/or FMS this is truly a medical issue and the decision must rest in the hands of the young person's physician in consultation with the youth. Some young people are able to participate in a physical education class providing that they can rest when they need to and can retain the right not to participate in specific activities, which worsen their symptoms. Others may not be capable of even modified participation. One approach is to have that youngster's physical therapy, combined with a report on its benefits, count for PE credit, rather than removing the Physical Education requirement altogether which may involve a lengthy process of obtaining permission from higher authorities.

### **The Physical Demands of Moving from Classroom to Classroom**

For most youngsters currently diagnosed and who do not use wheelchairs, the level of activity required just moving from classroom to classroom could be very draining. Furthermore, if it is required that students with ME/CFS and/or FMS carry books or other equipment, climb stairs or walk to outside buildings, there is an even greater likelihood of disabling exhaustion. For these young people, having a timetable arranged with the physical demands kept in mind can be very helpful. This usually requires careful planning before the school year begins. As well, if classroom teachers are willing to keep a copy of the relevant textbook in the classroom for the use of this youngster, physical energy is conserved. Providing a second set of textbooks to remain at home is also reported as very helpful in both conserving energy and accommodating to problems with memory.

### **The Physical Demands of a Classroom**

In the classroom, physical demands are also present. Simply sitting up for long periods can be draining for young people with ME/CFS and/or FMS. Brief rest periods can prevent fatigue from becoming overwhelming. A student with ME/CFS and/or FMS may be able to deal with the classroom more easily if the desk and chair are ergonomically suitable, if the student is positioned so that s/he is able to stand and stretch cramped muscles unobtrusively, and if the student is placed well away from drafts and in the warmest part of the classroom. Recess breaks in elementary and movement between classes may need to be modified if the student has difficulty with these aspects of school life because of muscle weakness or muscle spasm.

Sensitive and creative accommodations can be set up privately and be very helpful. If the youngster is able to refresh his or herself by resting the head on the desk for a while, a tactful teacher will make this a recommendation to all students from time to time. This way, the student with ME/CFS and/or FMS feels less singled out. If a rest on the bed in the school nurse's office is what is needed between classes, with a scheduled rest break provided for that purpose, nobody else need know of this plan unless the youngster wishes to share the information.

### **Teaching Strategies for Cognitive and Learning Problems**

Once it has been determined whether and how a young person with ME/CFS will attend school, whether in a traditional or alternative classroom, there remains the difficulty of addressing the cognitive and learning problems. The theories and the research evidence to date about the cognitive problems in ME/CFS do not yet give us confidence that traditional learning strategies such as are used with children who have attention-deficit disorder, learning disabilities and other well-known learning problems will work well. However, these methods may work with some young people with ME/CFS. Since knowledge about effective strategies for these problems is very limited, educational accommodations need to be based on a team approach in which teachers listen to the children's and parents' reports about learning difficulties, make their own observations of impaired learning processes in the classroom or in a home tutoring session, and find effective ways of addressing them.

### **Concentration**

Dr. Linda Miller Iger, in "Strategies for Learning with CFS", answers a letter about concentration problems from a young person:

Healthy adults can only concentrate for about 50 minutes, which is why high school classes are only that long. With CFIDS, your ability to concentrate for long periods of time is severely compromised. The best way to optimize the "window" of brain power is to test your attention span.

You can test your attention span by buying an egg timer and initially setting it for 20 minutes. Based upon my experience with CFIDS patients, 20 minutes is about the time you can reasonably expect to concentrate. If you find your mind wandering before the timer goes off, stop and look at how much time has elapsed and compute your attention span. You will find that your attention span will be different when you're relapsing than when you feel somewhat better.

You need to take at least a 10-minute break after each of these work sessions. During your break, do something as non-cognitive as possible. For example, go and get a glass of water or milk, look out the window, close your eyes and kick back. The goal is to string together three "cognitive" sessions with small breaks of 10- to 20-minutes after each of the first two sessions and a long break at the end of the third session. I hope this is helpful to you. Keep me posted on your progress.

### **Memory**

In an article entitled "Studying for Exams", Dr. Iger states:

...the answer to remembering material lies in looking at how mental processing ability is compromised in a person with CFIDS. Think of the mind in terms of how a computer processes information. The overall processing of information in a healthy

person and a YPWC is the same, but the actual processes take longer in a YPWC. It is as if the computer in which the CFIDS student processes information is slower than that of a healthy person. Therefore, in order to study better, a YPWC needs to give the brain more cues when trying to recall information.

For example, try to think in terms of things that are different or meaningful to you. This form of studying is one way that a CFIDS student will better recollect material. Some text notes are not easily absorbed. These notes should be written on a yellow legal pad of paper, since YPWCs sometimes seem to easily misplace things. The yellow colour provides intensity and brings attention to itself, so that a student is less likely to lose his or her notes. Use one or both sides of the legal page. Then, the student should read and say the notes out-loud. Rewriting the notes is also a good way to help remember material. This method of studying involves the visual, kinaesthetic and auditory methods of learning. It helps to lay the memory down and bypass short-term memory.

The night before a major exam, it is strongly recommended that the CFIDS student write out answers to the questions he or she thinks will be asked — sort of like pretending to write his or her own exam. By doing this the student will be forced to think like the instructor. Then, after completing and checking the practice exam, the correct answers to missed questions should be written on the legal pad and studied.

## **Energy**

In "Energy Saving Tips for YPWC Students", Staci Stevens writes:

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 more sleepy 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.

It is not clear whether all the cognitive problems in ME/CFS and/or FM can be explained by this concept of "lack of oxygen to the brain". However, what is known for sure is that ME/CFS and/or FMS are not like depression, an illness where effort and activity are usually therapeutic. When you push a person with ME/CFS and/or FMS too hard, whether they are young or old, you are likely going to make learning much harder as well as make them feel ill. This is not to say that there may not be young people who will respond well to being pushed a little. The group of youngsters diagnosed with ME/CFS and/or FMS includes children and adolescents at various stages of the illness, and some, but by no means all, may be affected more by secondary depression than by ME/CFS and/or FMS by the time they reach your classroom. As we stated earlier, the question of activity management is a very individual matter and must be dealt with on an individual basis. Consultation with the young person and their team, combined with teachers' objective observations, is the way to make decisions about activity level. It is very important not to make assumptions.

## **Time Teaching Sessions for A Child's Window of Alertness**

In "ME and Learning: Problems and Solutions", Colby and Jacobs state that:

The [teaching] sessions are best timed for the hours of maximum mental arousal. The brain's Reticular Activating System (which keeps us alert) is typically disordered in ME (lesions are visible on MRI scan) and patients have to learn to do mental work

at the most productive time according to the rhythm their brains have adopted. This is often, in fact, the afternoon or even the evening, but it does vary.

### **Creative Accommodations**

There have even been suggestions that sofas be provided in classrooms for all youngsters who need to rest occasionally. We know of several professional people with ME/CFS and/or FMS who make the use of such sofas in the workplace. It is therefore not true that such an accommodation does not prepare a child for 'the real world'. Although some have suggested that this type of accommodation could stigmatise a child, we remind teachers that sometimes accommodations for young people with ME/CFS and/or FMS prove to have benefits for other children whose individual needs arise for a different reason.

Schools can make flexible accommodations. A parent reported that her daughter with ME/CFS was permitted to sleep in the school bus during outings. By the time the bus returned to the classroom, this young woman felt refreshed and, most importantly, included in the day's activity.

The National CFIDS Foundation (1998) makes the following suggestions:

Prior to the first day in class, all hallway or other passes, and a second set of textbooks should be issued. Each person with whom the student interacts (including personnel outside the immediate teaching staff), needs to be aware of the student's access needs (hallways, bathroom, etc.).

Accommodation may need to be made to transport the child to school if s/he is able to attend. A bus ride may be too taxing (sensory overload, extended periods of sitting, nausea with motion, fumes from the bus) to allow for strength to be left to walk to and be alert in class.

A student may need a quiet place to lie down after getting to school, and/or between classes.

A student should be allowed to be late for class without sanction. There will, in all likelihood, be a good reason. Often students need more time as their pace is slow. Forgetting where the next class is or how to get there is not unusual. Sometimes transportation between classes is needed.

A separate option for lunchtime might be welcome. Lunchtime may be a difficult period for the student. At the very least, the child leaves the noise and confusion of the cafeteria setting sapped of energy, and light-headed. Food smells can also contribute to increased nausea.

A buddy system might be established in the event the student has to leave the classroom. Syncope, fainting, muscle weakness, balance problems, and impaired depth perception create a risk of falling.

The student might need to carry a pack or other bag with additional clothing, beverage or food. A buddy would be helpful in this instance as well as helping with textbooks and other materials.

## Tests and Examinations

In "School Examinations and ME - Special Assessment Arrangements", ME researcher and educator, Jane Colby, comments:

We all know only too well that examinations and ME do not mix, because of what I like to call "mental fade". However, they are a part of educational life and, like all education, they can be modified to suit the needs of children and young people with ME. Special arrangements should be requested as matter of course, well in advance if possible. ME severely disadvantages pupils in exams due to the fatigability of the brain, and special provision helps to reduce that disadvantage, thus maximising the chances of a good mark.

In "Guidelines for Schools", the National CFIDS Foundation recommends the following accommodations for tests and examinations:

**Flexible Scheduling:** Extend the time allotted, or administer in several sessions during the same day or over several days.

**Flexible Setting:** Administer the test in a separate location with minimal distractions.

**Revised Test Format and/or Directions:** Read the directions and/or the questions, large print, changing the spacing, location or size of the answer spaces or type of question, fewer items on each page, modification of the test content.

**Testing in General May Present Problems:** If you think about it, the student has fewer hours in which to function in general. Therefore, it may take longer to shower and dress than the non-ill peer. It will take twice as long to study the same material. Because s/he wants to do well (perform at the pre-illness state), s/he studies perhaps longer than recommended. What follows is the inability to take the test at all because of relapse from preparation. The same happens with projects.

## The Long Term Goal

As we stated earlier, a small group of young people remain significantly ill and disabled. When the future is so uncertain, it can be difficult to remember that the goal of children is to have a childhood with all its spontaneous learning through play and an adolescence that involves the typical developmental tasks of other adolescents. Somehow this goal must be honoured despite (and maybe by) all this uncertainty and by having to plan carefully.

The long-term goal is to preserve the student's future as an independent adult. In order to do that, these students, as any others, need to complete as much education as they can. As with any student, it is not necessary to dwell on career choices until the student reaches those turning points but it is essential to make the most of the student's positive attributes in case the illness limits some options.

## Self-Monitoring

Over time, self-management of the chronic illness is an essential goal for the young person with ME/CFS and/or FMS. Teachers can play a role in fostering self-management, under the direction of the child's team. For example, in the classroom, teachers can encourage the student to self-monitor for excessive energy depletion or increased pain, to let you know when

energy or pain problems arise and to suggest the option needed. If you notice signs and symptoms before the student becomes self-aware, ask the student what is needed. A change of position or a short break may be enough. Changing the demands of the activity may suffice. For example, an activity that requires co-operation with others is more demanding than an independent one. Since it is most important to respond to these symptoms quickly, it is helpful to have options or procedures in place to make it easy to respond. Where can the student rest - a quiet place in the classroom or another location in the school? If that is not possible, where else can the student go – to his/her home or a prearranged neighbour's home? How will the student get there without making symptoms worse? It will be up to you, the parents, the student and, perhaps, other school personnel, to consider the possibilities and come up with workable options. You and the student will be the ones to put the plan into operation as needed.

## **Coping**

Self-regulation is one aspect of coping but coping with a chronic illness is a complex issue. Bell and associates (1999) have discussed the research and clinical experience on coping and noted that there is no single coping style that is adaptive in ME/CFS and/or FMS. Their chapter on coping emphasises the following aspects: diagnosis, denial, losses and grieving, depression, anger, fighting the diagnosis, reaching out and sharing, identity formation and acceptance. Schools, teachers and peers can potentially play either a positive or a negative role in the process of adaptation and the facilitation of coping. Identity formation in particular is an aspect of adolescent development that may be especially challenged by the impact of ME/CFS and/or FMS.

Health identity confusion was discussed earlier and may be a complicating feature in identity formation with some youngsters. Young people who were once athletic, hard-working students, sociable and respected by teachers suddenly find their grades falling, their athletic activities impossible, friendships falling away and relationships with adults altered. Although they cannot remove all the pain these young people experience, teachers can greatly help them face these devastating changes and to rebuild their sense of self by setting up educational plans that are built on trusting relationships and promote task mastery. Helping young people envision themselves doing well in the future, in spite of the lack of certainty of a return to health, is an educational mission of the utmost importance.

## **The Importance of Prioritizing and Flexible Planning**

Prioritising and flexible planning are the keys to success. With educational goals also in mind, success is more likely to be achieved if priorities and plans are also organised around the five principles of adaptation to ME/CFS and/or FMS:

- Conserving physical, mental, and emotional energy
- Fostering achievement of age-appropriate developmental tasks
- Maintaining the zeal to learn and the motivation to try new things
- Ensuring a gradual and self-respecting adjustment to limitations
- Fostering a positive and optimistic outlook, regardless of possible outcome

## **Set an Achievable Goal**

In “ME and Learning: Problems and Solutions”, Colby and Jacob suggest:

A suitable first qualification for the child to aim at is the subject which s/he finds easiest, given the cognitive deficit which is handicapping educational achievement.

Having a serious and genuine aim can be very therapeutic in keeping up morale and boosting self-esteem, which takes a severe knock in this disease. Gaining qualifications is also of very great relevance to a child whose future has suddenly become uncertain.

### **Educational Objectives**

It is vitally important to focus on the enormous strengths that these young people have and not to assume that, because there is an impairment of some cognitive processes, that the child is incapable of grasping complex material. For example, if a child was identified as gifted before he or she became ill, that information should be taken into account in educational planning. It is as detrimental for an extremely bright child with ME/CFS and/or FMS to be given pointless work, or work that is too easy, because of a misunderstanding of his or her cognitive difficulties as it is to give very challenging work to a healthy child with a severe, global intellectual disability (formerly known as a mental handicap).

While adaptation to the illness and its limitations must be incorporated into educational planning, teachers must keep in mind the fact that education in and of itself is a right of all young people. Many youngsters with ME/CFS and/or FMS are very bright and capable students. They need as much enrichment and stimulation of their intellectual capacities as any child. It is not desirable to offer them a 'watered-down' curriculum as a way of addressing cognitive and other types of fatigue. The contributions of young people with ME/CFS and/or FMS on the international web sites demonstrate just how very capable these young people can be if given the opportunity. (You will find a list of web sites featuring articles by these youth at the end of this Sourcebook.)

In "Focussing on Children", Jane Colby states:

We must develop a focused curriculum for each student, which means reducing it to a few key subjects in which they are interested, to avoid dissipating the little mental energy they have. We must adopt the concept of end-on exams, which means sitting examinations singly i.e. not all in the same year, perhaps beginning at an earlier age than usual. These exams need to be taken in ME-friendly conditions, which may be the home. One boy of 13 has in this way achieved a starred A grade in History [exam], normally taken at 16, despite chronic disabling ME/CFS, and he is not an isolated case. We must therefore aim at longitudinal achievement, so as to build a portfolio of qualifications year by year rather than imposing a huge programme of simultaneous exams, which forces down the grade achieved and may even force students to pull out altogether. Health before work is also a Key Concept. Just as the old Hippocratic Oath involves promising to "do no harm" so the way we educate children with ME/CFS should also do no harm.

### **Prioritizing**

Prioritising requires knowing what goals are available and choosing from them. In making choices with students with ME/CFS and/or FMS, consider the three points: conservation of energy, progress toward the long-term goal and the student's wishes. The people who know the student best, usually the parents and the student him/herself, will undoubtedly have some long-term goals in mind. These will help establish priorities when choices have to be made whether academic or social. Teachers can help identify short-term goals, both social and academic, which will further the long-term ones.

Prioritising is important in anyone's life. For example, you have to decide whether to go out to the movie or to go to bed early and be ready for the test next day. For people with ME/CFS and/or FMS the choices become much more basic. For example, the person may make supper preparations first thing in the morning or risk ending up that day with nothing to eat and not enough energy to prepare it. The basic requirements of life must be prioritised – food, personal hygiene, clothing, some form of exercise, and some social interaction. For students, growing and learning must find their place in the queue for energy. In setting priorities, everyone (child, parent and teacher) should be honoured in some way.

## **Planning**

Insure that at the end of one school year the plan for the next year is in place. This should ensure that all services, including tutors if necessary, are in place so there is no delay in beginning the next year. Presuming the child will recover during summer vacation is unreasonable. It is safe to assume the services necessary at the conclusion of one year will still be needed in the following year. (National CFIDS Foundation, 1998)

Planning requires knowing goals, knowing resources available, knowing different strategies and choosing appropriately for success. Resources available limit the strategies that can be used. Resources can come from both the school system and the parents and include funding, personnel, educational materials, transportation and time.

## **Routines**

Routines, the same things happening on a daily basis (time to rise, time to go to school, time to eat, time to go to bed), provide most children with a sense of security and most children, most people, save time and accomplish more with consistent routines. Parents and teachers spend a lot of time establishing routines with children. Unfortunately, with ME/CFS and/or FMS, routines may be disrupted, especially if the condition is severe. If they have expended a lot of energy one day, then they will not have as much the next day. This is upsetting for everyone concerned. Being upset and the constant necessity to make decisions drain even more energy.

In this case, sets of procedures may help, a sort of Plan A-Plan B Routine – the basic routine with points at which it can be modified and plans for what to do at those points. Planning for flexibility gives everyone more peace of mind, a sense of security so important to childhood, a sense of control so important to adults.

There should be routines to follow when the child is going to be late for school, when the child needs to rest during the day, when the child must go home from school early, when missed work needs to be transported home, when finished work needs to be transported back to school, and when the parents and teacher have a regular review of procedures. Knowing what to do and when to do it, liberates everyone from anxiety and confusion and leaves us free to turn to living and learning. Agreeing on and writing down procedures is one part of planning.

## **Habits**

Routines have more to do with scheduling while habits have more to do with strategies. One habit that is very useful in conserving energy is breaking tasks into small separate steps. That way the amount completed can be matched closely to the amount of energy available. Energy drain from frustrated attempts to complete longer blocks of tasks is thus avoided. Energy boost from tasks completed is maximised. Teachers are great at breaking learning into small steps and are great allies in establishing this habit. Making lists is another helpful habit. It allows

prioritising and sequencing to conserve energy. It also saves energy because one does not have to keep everything in mind and keeps one focused on necessary tasks. Planning backwards follows from the list making. If there are significant activities that must be accomplished late in the day, then the person with ME/CFS and/or FMS can plan to conserve energy earlier. The same goes for planning a week. If there is going to be a busy day late in the week, plan to conserve energy earlier.

### **The Long Range Plan**

A long-range plan is a cross between a curriculum outline and a calendar of events. The teacher takes the period of time allowed for the material and decides how much time to spend on each topic, what overall strategies to employ, what deadlines and special events must be penciled in and what sets of materials to use. There is usually a long-range plan for each subject. The plan might cover a unit, a semester or term or even a whole year. The plan is usually one to five pages in length.

It is difficult for teachers to make a long range plan if there is no curriculum set by the Board of Education. Curricula take a lot of experience, knowledge and decision-making. It is rather unfair to expect individual teachers, especially new teachers, to invent a curriculum when the Board has not. However, in the absence of a curriculum, a teacher could use an approved text to supply a series of topics for the subject. An experienced teacher may know the subject so well that she can make up a long-range plan with reference to neither curriculum nor text.

A long-range plan is an invaluable tool in adapting a program for a student with ME/CFS and/or FMS. The teacher needs to emphasise to the parent that this is a plan only and one cannot predict what roadblocks or opportunities may present themselves along the way. What actually occurs will be different inevitably in some ways from the plan.

However, the long-range plan allows student, parent and teacher to keep firmly in mind what learning/performance is required for successful completion of this course/unit.

It allows parent and student to make every effort to have the student present for parts of the plan, which cannot be replaced in other ways. Some experiences are just not reproducible. It allows everyone to suggest alternatives for some parts of the plan, e.g. texts or reproducible materials for classroom activities. When long-range plans for all subjects are compared, it allows for integration in which one book can be read for two purposes or one project to fulfill two requirements.

### **Example of a Long-Range Plan** (this example can be adapted for all grade levels)

<b>Poetry Unit: Six Weeks</b>	
Every Day	Silent reading of poetry books for 15 minutes; writing about what was read for 10 minutes. Reading aloud and discussing what was written for 10 minutes. Students are expected to improve their ability to notice the following about poems: effect on the reader whether evocation of emotion or memory, meaning, format, rhyme, rhythm. Ongoing evaluation of the writing and discussion to track students' knowledge of these attributes of poems.

Week One	Visit to school Resource Centre to become familiar with poetry section and to take out poetry books of interest. Setting up of poetry centre in classroom. Letter home about unit. Establish reading, writing, and discussion routines. Introduction of project in which students write and illustrate a poetry book of their own by the end of the unit.
Week Two	Lesson on writing Free Verse. Lesson on formatting poems. Completion of first poem for project.
Week Three	Lesson on writing couplets. Lesson on illustration of poems with a visit from a professional illustrator. Completion of second poem for project.
Week Four	Lesson on writing quatrains. Lesson on memorizing. Completion of third poem for project.
Week Five	Lesson on writing Haiku. Lesson on writing limericks. Completion of fourth and fifth poems for booklet.
Week Six	Lesson on assembling poetry booklets including Table of Contents, pagination, dedication, acknowledgments. Presentation of memorized poems. Completion of projects. Display of projects and visit by Poet for a reading. Evaluation of projects according to project sheet.

### **Adaptations of the Six-Week Plan for Energy Conservation**

1. There are a number of aspects of this plan, which cannot be reproduced, e.g. the visit by the illustrator and the visit by the poet.  
Parents and student should try to make sure that the student has enough energy to attend school for these events or accommodations might be made, with the permission of the performer, to videotape the event.
2. The lessons on the forms of poetry might be replaced with a text or reproducible activity. These should be prepared and held in readiness in case the student misses these classes.
3. There are some things that could easily be done at home. The student could read the poetry books and write about poetry at home. A book and notepaper should be held in readiness at home for these. If the discussion is missed, then the student's only avenue for improvement will be comments by the teacher on the written work. If the parents are willing and able, they can augment by reading and discussing with the student.
4. The poetry project can be completed at home as well, so materials and a duplicate of the project instruction sheet should be held at home ready to use when energy allows. The teacher might allow the parent to type the student's drafts and suggest less taxing forms of illustration such as magazine cutouts or photos. Or the illustration can double for a project in Art class.
5. If memorization of the poem is going to present a cognitive impossibility, the student might practice a dramatic reading instead.

If presenting in front of the class will be too draining, the poem could be audio or videotaped at home. Another possibility would be to arrange a small audience of teachers and peers well known to the student.

## **Resources Required for Adapting This Long Range Plan**

1. Dates for the illustrator and poet visit.
2. Text or reproducible pages about the poetry forms and a means of transporting these home and back to school if necessary, e.g. another student, tutor, parent, etc. E-mail may prove helpful too.
3. A poetry book and writing materials. Again, a mechanism (such as e-mail) for transporting the written work to school and back home, if necessary. Time for the parents or a tutor to read and discuss some poetry with the student.
4. Materials for the poetry booklet (e.g. paper, magazines, scissors, glue, coloured pencils, stencil, computer or typewriter, Bristol board.). Time for parent or tutor to type or write out final drafts of student poems, if necessary. Transportation of materials home and finished booklet to school may be required. Coordination with the art teacher, if necessary.
5. A poem of the student's choice. Time for parent or tutor to practice the poem with the student either for memorization or a dramatic reading. Audio or videotape recorder and tape. Transportation of tape to school.

## **The Timetable: Another Tool**

Parents might expect that timetables could be arranged so that the student with ME/CFS and/or FMS could receive instruction in core subjects at the optimal time of day. However, there are difficulties in doing this.

A timetable is usually prepared for a block of days whether semester, term or whole year. Timetables are necessities for groups of classes who must share facilities, e.g. gymnasiums, libraries, classrooms or personnel, e.g. music, language, physical education, second language or special education teachers or educational assistants. A timetable taking into account all these factors is a complicated document.

Classroom teachers may have only a limited control over aspects of the class timetable.

The other stumbling block is logistical. A great deal of teaching time is lost to logistical matters, e.g. student movement in and out of classrooms, settling down after movement, setting out or cleaning up after activities, announcements, interruptions for drills or announcements, collection or distribution of notices, work, forms, money, permissions, etc. More teaching time is lost to interruptions with discipline, illnesses, parents, other teachers, and special events. Some days, the amount of teaching time actually available seems minimal.

All that said, the timetable might be a useful tool for adapting the program to conserve the energy of a student with ME/CFS and/or FMS. Since many timetables are set far in advance, it's best to start in the spring for September implementation. In that way, the school can be aware of the requirements and have a chance to include these parameters into the many others that are involved.

If the first half hour or last half hour of the day is taken up with administrative tasks, the student might have permission to arrive late or leave early always supposing transportation can be arranged. If the teacher has flexibility in the timetable, it may be possible to schedule core subjects to accommodate the student's best time of day. With the most ill students, choices that will have a larger impact on the student's future may have to be made, e.g. dropping

classes such as second languages. These decisions will have to be made with consultation of all concerned.

If the transportation and personnel problems can be overcome, you could identify parts of the day that may not be as essential for this student. If the student is receiving physiotherapy or has a prescribed amount of exercise, then perhaps physical education classes are not appropriate. This might be a rest period. Alternatives to participation might be found in learning rules, strategies, physiology or if teamwork is the goal, helping the team in some other way such as fund-raising.

If music is instrumental, percussion might be the answer or substitution of a vocal program, if that is more appropriate. Again, a rest period may be more urgent.

### **A Note About Career Planning and Post-Secondary Education**

As research on outcomes of young people with ME/CFS and/or FM has been accumulating in the past decade, more attention is now being paid to long term disability issues as well as career and educational planning. The National ME/FM Action Network Youth Project will be exploring these avenues and posting information about research findings and best practices on our web site. We urge teachers, school counsellors, school psychologists, families and youth to stay in touch with us as we move into these areas of advocacy.

### **More Research on Outcomes is Needed**

Educational researcher, Dorothy Morris (2001), is leading the world in exploring the question of educational outcomes. She gathered information from forty adults, twenty-nine females and eleven males, ranging in age from nineteen to sixty-two years. The duration of ME/CFS (Ramsay Criteria) was from nine months to twenty-five years with a mean duration of eight years. She found that there were profound difficulties experienced by all forty participants with cognitive dysfunction attending post-secondary institutions in Australia.

We hope very much that educational researchers will look at all aspects of the educational needs of school-age children and adolescents with ME/CFS and/or FMS. There has been pioneering work conducted in the United Kingdom (Dowsett & Colby, 1997), in the United States (Bell et al., 1999) and in Australia (Stephenson, 1998; Stephenson et al., 1999) but, to the best of our knowledge, there has been no educational research conducted in Canada. While we are waiting for that research, we have to do what we can to help these ill children.

### **Suggestions from Teachers, Parents and Young People**

1. Remember, each young person with ME/CFS and /or FMS is an individual. Some need more accommodations than others; special strategies will work with some and not with others.
2. Schedule classes during the student's 'window of activity and alertness' when possible, especially classes requiring intense concentration.
3. Permit the student to tape record classes. Provide necessary equipment.
4. Permit the student to eat energy-producing snacks at times dictated by the student's blood sugar levels rather than restricting eating to official snack-times.

5. Reinforce the aspects of self-regulation recommended by the family and child's trusted medical team.
6. Adapt teaching to the student's most efficient learning style. Even mild learning differences or weaknesses may be amplified in ME/CFS and/or FMS. However, great strengths may also help a young person to compensate for areas of weakness.
7. Be aware that some students are negatively affected by noise, odours, fluorescent lights, heat, or cold. A physically comfortable student will be a more effective student.
8. Permit exhausted students to rest or recover their concentration by resting their heads on their desks or by finding a quiet place to rest. Note that many young people and adults with ME/CFS and/or FMS find that there is an urgency to lie down to recover in any fashion. The student may be able to rest in the nurse's office.
9. Give advance notice to the student (and perhaps the family) when a big project or an exam is coming up.
10. Permit more time to get to and from classes because of the fatigue and 'spatial confusion' factor.
11. Remember at all times that the length of time this student can concentrate is likely very short at all times but will vary with the young person's state of health. Do not underestimate how long an average school class requires concentration.
12. Because concentration is always better on subjects of intrinsic interest, try to design curriculum items and exercises around a youngster's current interests.
13. Set up a 'buddy system' with other students so that students can share notes and help with homework missed during periods of absence.
14. Try setting up a study carrel to see if reducing competing stimuli aids in concentration. Observe objectively. Some youngsters with attention deficits find this method more, not less, handicapping.
15. Be sure that every relevant person in the school knows of the diagnosis.
16. Teach the student 'mnemonic' strategies - gimmicks to aid memory. These include, developing acronyms for remembering key facts or theorems, extra rehearsal, multi-modal learning (hearing and seeing the items at the same time).
17. Encourage the student to write out key information as a way of helping to get it stored in memory.
18. Permit a youngster with weak fine motor skills and lack of motor energy to use energy-saving devices such as computers.
19. Recognise and allow for the extra amount of time the student may need for learning, studying and producing new work.

20. Understand how anxiety can intensify the learning problems that can accompany ME/CFS and/or FMS. Model a confident and non-threatening approach to the student.
21. Give frequent evaluation, framed positively, to help maintain motivation.
22. Obtain a handicapped-parking sticker for the student who drives, or for their family, to permit close access to buildings.
23. Consider giving brief oral tests instead of written ones to establish whether basic competency has been achieved.
24. Permit the student to submit at least some work on audiotape instead of in writing. Writing may be both physically and cognitively draining for the student.
25. Make good use of computers. Many youngsters with ME/CFS and/or FMS are highly computer-literate and the fast pace of computerised information may help compensate for attention deficits.
26. Provide ergonomically appropriate chairs if possible.
27. Think of creative ways to provide alternatives to 'field trips', such as telephone interviewing assignments, assignments based on outings such as visits to a clinic or to relatives or from 'virtual' trips taken by videotape or Internet to other countries.
28. Use letters between students to serve as 'bridges' with the homebound child as well as writing exercises. Practical problems can sometimes be overcome by giving the child extra time or rests during the exam (if permitted). However, exams may be quite impossible on intellectually low days, despite extra support. Special concessions should be asked for and as much notice provided as possible.
29. Help conserve physical energy by adjusting demands for physical activity to the child's current state of illness or disability.
30. Factor in the amount of 'hidden' physical activity as part of a youngster's daily amount of exercise.
31. Be sure that ramps and elevators are available for the young person who uses a wheelchair or who needs to save energy.
32. Consider the physical layout of the school and the youngster's timetable and adjust according to physical demands.
33. Permit modified participation in PE, permitting a youngster rest breaks or participation in just some of the activities. Do not REQUIRE such modified participation if it humiliates the young person.
34. If participation in PE goes against medical advice, it must not be required. Consider adapting the PE curriculum to fit the student's participation in other forms of physical activity, including physical therapy, and design a theoretical component if necessary for academic credit.

35. Replace PE with an independent study course or another subject.
36. Remember that physical ability is highly valued in our culture and especially among youth. Treat physical limitations with sensitivity and tact.
37. Remember and factor in a youngster's physical limitations when sending work home, advising tutors or scheduling meetings at the school.
38. Plan transitions back to school with great care, keeping the physical demands of each new stage clearly in mind.
39. Demands for activity must decrease or increase according to medical advice in consultation with the youth and family. In nearly all of these transitions a gradual approach is necessary. Attendance is likely to be somewhat erratic, with good days and bad days, during the transitional process. The reality of ME/CFS and/or FMS requires unusual flexibility and awareness from school personnel.

## Chapter 6

# The Student and Family

By

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### **Considerations in Developing an Educational Plan**

In the world of special education there are many issues to be considered when designing a plan for a child with a disability, chronic illness or other special needs. While in the United States there are general laws about accommodating children with disabilities, in Canada policy is established on a provincial basis. The specifics are often left to the discretion of the individual province and even the individual school district (to obtain provincial policies, see the listing of Ministries of Education, province, at the end of this Sourcebook). Although special education is not enforced by legislation, Canadian parents have recourse to Canada's endorsement of the United Nations' Convention on the Rights of the Child in arguing for special services for their children.

Currently, in Canadian schools, it can be hard to find a suitable placement for a child who is unable to attend to school or succeed in a regular classroom environment. There are undoubtedly economic factors affecting the provision of special education services to children. Lack of funding is a common barrier. For these reasons and others, parents of children with ME/CFS and/or FMS are becoming advocates for their children's education. They are becoming proficient in the educational principles and policies that pertain to their children's special needs and confident in seeking the services their children need to succeed in school.

### **Inclusion**

In recent years there has been a strong movement towards inclusion in Canadian schools. Children with special needs are being placed in regular classrooms and non-specialist teachers find that they need to become more aware of the principles and practices of special education. One of the critical features of special education is the involvement of families in the development of a child's individual education plan (IEP). It is widely accepted as best practice that parents must be involved from the very beginning in a child's individual education plan, throughout transitions and even into post-secondary planning. This concept of including parents in educational planning may not be familiar to teachers who have not worked in special education settings. This chapter is therefore provided in the hope that teachers will recognise the importance of parental involvement in all stages of educational planning for the child with ME/CFS and/or FMS.

### **Knowledge about ME/CFS and/or FMS**

Parents of children with ME/CFS and/or FMS play a critical role in providing teachers with important information that will enable teachers to modify the educational environment and the curriculum to meet their individual child's special needs. It is amazing how well-informed parents of children with special needs can become when dealing with complex medical matters related to their child's illness or disability. However, this should not be too surprising. They are

there at the beginning when the child first identifies symptoms and they follow the arduous journey in seeking a diagnosis and hearing explanations and recommendations from their child's clinicians. Once their children are diagnosed, parents may obtain the latest research from their doctor or from advocacy organisations. They may consult educational experts to learn what type of education works best for children with the particular disability in question. Most importantly, like all parents, they are in a unique position to provide information about many aspects of their children's development. Interestingly, too, parents often downplay the disabling symptoms and instead emphasise their children's positive qualities, abilities and interests. Their special knowledge and commitment to seeing that their children's rights are met make these parents very important partners with the teachers in ensuring that a child's experiences in school will be successful. Parents of children with disabilities must often go to great lengths to see that their children's rights are met and that their child receives an appropriate education.

### **Young People are Partners in Educational Planning, Too**

Children and adolescents with ME/CFS and/or FM can also be very astute about the ways in which the illnesses affect them. They also know their own interests and strengths, critical ingredients in educational planning. They are always the experts on how they wish to be seen and whether they are comfortable with others knowing about their condition. As young people leave puberty and enter adolescence, they need to be included more and more educational planning. Such involvement plays a critical role in fostering self-management and a sense of efficacy, of being a person in control of one's own destiny. The youngster who is given the opportunity to provide input into his/her schooling is often more committed to trying, more open in revealing when he or she is floundering, and more resilient in coping with setbacks. These qualities can lessen the degree of disability posed by the condition.

### **Teachers Have Unique and Essential Contributions to Make**

Teachers also have unique contributions to make to the educational plan for an individual child. Along with being the experts on their subject matter, teachers know a great deal about teaching, and the best way to 'reach' an individual child! While the family and youngster know their own situation well, teachers can often see 'the bigger picture' from their work with many children. This perspective can be very useful in helping both the parents and the student see that many share their difficulties and that they are in fact experiencing a 'normal', though intensified, situation. Teachers also know what they can and cannot manage in the way of an individualized approach and they can help make plans more concrete and realistic as a result. They may be able to help families to find their way through the complex maze of services for children who need extra help. They can serve as powerful advocates at team meetings. It is often the teacher's willingness to adopt a plan that determines whether or not a school-based team or district will approve a service.

### **The Unique Circumstances of Families with Children with ME/CFS and/or FMS**

In general the situation for families of children with ME/CFS and/or FMS is much the same as any family of a child with a chronic illness or disability. When working with families of a child with ME/CFS and/or FMS, teachers can use much of what they have learned from working with other families of children with disabilities. Teachers and parents will want to create an environment conducive to building a partnership. Respectful communication and the willingness to learn about the specifics of the child's illness will go a long way in creating the good will that will help parents trust in the partnership. For example, when a child is tired all the time, a teacher may want to be helpful by suggesting to the parent that a regular bedtime routine be instituted. However, the teacher may not realise that sleep disturbance is one of the biggest

problems in ME/CFS and/or FMS and is often an enormous challenge to both parents and doctors to correct.

It is also critical to work with the child's entire care team, including the family, special education teachers, and the physician. In this chapter we would like to address some of the special issues that many families of children with disabilities face but which are particularly intense for families of children with ME/CFS and/or FMS.

As was mentioned in Chapter 3, "Medical Aspects of ME/CFS", these illnesses are complex conditions about which many doctors are not yet well educated. While ME/CFS and FMS are recognised by the World Health Organisation, physicians around the world still have a problem understanding how to diagnose these illnesses. Part of the reason for the difficulty is the lack of any definitive marker for the illness. (The diagnosis of ME/CFS in particular is a diagnosis of exclusion, whereas in the diagnosis of FMS there are physical signs to be sought.) Many doctors, because of the way they trained, want to be able to run tests in order to establish a diagnosis. If no abnormality shows on testing, many doctors tend to think, erroneously, that either they haven't run enough tests or that the problem is psychological.

### **Obtaining Special Educational Services**

When parents start seeking accommodations for their child with ME/CFS and/or FMS, they are often advised to contact the school district's department of Special Education. Some families are reluctant to do this and strive to work with the classroom teacher alone, hoping that no special applications or special categories will be needed. Children and parents sometimes fear that there will be a stigma attached to children who are classified as 'disabled'. Our view is that children with ME/CFS and/or FMS are already 'labelled' with the name of the illness. They are children with health impairments, impairments that affect their ability to attend school and to learn in the same way that their healthy peers do.

There are also children with ME/CFS and/or FMS who do not meet the criteria for services under special education because they are managing to maintain grade level. A number of these youngsters do require modifications to their education in order to succeed academically. Without assistance they will slowly fall behind their classmates and fall through the cracks of the educational system. For these children, parents have reported to us that they usually had to apply policies under the Special Education provisions of their province, regardless whether their doctor or they felt that their child should be seen as 'disabled'. The fact is that a child with ME/CFS and/or FMS is a child with special needs in a very literal sense.

Parents can assist teachers by informing teachers about the 'triggers' that precipitate a 'crash' in their child. Explaining the flushed cheeks may help teachers to witness a down spell coming. Sometimes watching a child's posture, viewing how the child is interacting with peers, or noting a glazed expression in the child's eyes, can help a teacher to understand the subtle clues of an impending crash. When teachers truly understand the waxing and waning of the physical and cognitive symptoms in ME/CFS and/or FMS, they will be in a better position to suggest accommodations. Specific ways in which teachers can make accommodations were addressed in the previous chapter. However, we would like to consider several other areas of a child's life that teachers need to acknowledge and address in educational planning. These are: socialization, family life, and the special sensitivity needed when the child has a parent with ME/CFS and/or FMS, too.

## **Socializing**

Special educators have for a long time acknowledged that social development is a key goal of education. Regular classroom teachers have also realised that a child who does well in school but has no friends is a child who needs help. Learning to socialise is as much an educational objective as is academic achievement. Children with ME/CFS and/or FMS may be very isolated from social contact with peers. It is often critical for the school to recognise the need to help these children with socialising. Teachers often don't fully appreciate the powerful role that they can play in assisting the child with ME/CFS and/or FMS to maintain social contact. However, there are many things that teachers can do to encourage peer interaction. If a child is unable to attend school on a regular, daily basis, the teacher can at least encourage the child to attend for special events such as class parties, assemblies, field trips, or class speakers.

Some students have found that corresponding by email with their class is one way to stay aware of what is happening in the classroom. This is especially useful for the younger sufferers of the illness. Some teachers have periodically had the class write notes or postcards to the homebound classmate, reminding them that they are thought of and still a member of the class even when attendance is impossible.

If the child is well enough to manage a class trip to a museum but unable to tolerate the bus ride to and from the site, a parent may choose to be a chaperone and follow the bus to and from the event. Special requests of this kind can often be accommodated if the family is given a chance to attend and to assist in planning the activity so that their child can participate.

## **Life for the Family**

ME/CFS and/or FMS pose significant challenges to family life, due to the puzzling and fluctuating nature of the symptoms. As well, the long period of dependency on adults is particularly problematic for adolescents. At a time when teenagers are usually moving away from their families emotionally and seeking support from outside sources, children with ME/CFS and/or FMS may be clinging to their families for their very survival. This is what one father said:

I had looked forward to the time when my son and I could share our love of baseball on the playing field in high school. He had been a star athlete in the mini league team that I coached and was heading towards being a star on the school team. But after ME/CFS hit, our life changed. We have lost the bond we had over sharing our love of sports together. He is no longer interested in watching the games on TV with me, because it's too hard to realise he can no longer play them. Sometimes he is unable to even tolerate watching the TV as it gives him headaches. I don't know what to do. I know he still needs me, but I don't know how to 'connect' with him anymore. The things we used to do together like going jogging, or playing basketball is too much for him on most days. And when he does push to do these activities with me, he often suffers physically for it later on. I don't know what to do, or how to be the father my son needs.

The fact that not all symptoms of ME/CFS and/or FMS can be completely removed with treatment means that families and children suffer deeply from the daily experience of illness, pain and exhaustion. ME/CFS and/or FMS are life altering illnesses, and not just for the child. As a mother shares her feelings tears well in her eyes:

When Katy was in kindergarten she was everyone's friend. She was an active, intelligent little girl. Now she spends all her days at home with me in pain. She is 9

years old and has been ill for over 4 years. She doesn't understand why the doctors can't make the pain go away. Why can't they give her something to stop the pounding headaches, the muscle pain that makes walking to the other room like climbing Mount Everest, or the constant abdominal pain? Day after day friends walk by the house on their way to school, and Katy sadly watches them from the living room sofa, longing to be like them. A mother is supposed to be able to kiss away the hurts and pains of a 9 year old child, and all I can do is rock her back and forth and tell her I love her.

Another parent states: "Some days life in our family is 'a roller-coaster' of emotions." The unpredictability of the illness, with frequent relapses and periods of feeling unwell appearing out of the blue, make every day a challenge. Plans we take for granted in our life, like going to the supermarket, or going out to dinner, can be forever in limbo for these families. They learn to never make plans too far in advance, or without a back-up plan. Parties may be cancelled at the last minute, holiday plans may become quiet gatherings at home, a Saturday excursion to the mall or an amusement park may be cut short or cancelled altogether if symptoms suddenly appear. Parents have to always be ready for the symptoms to flare up and for all their plans to be cancelled. It is hard to explain to the healthy sibling why you may have to cancel at the last minute. And if only part of the family goes to an event, it just isn't the same.

When teachers understand how this unpredictability affects the family, it is easier for them to understand the fluctuating attendance, and inconsistent workload of their students with ME/CFS and/or FMS. These children can never really count on themselves to be feeling good when needed. They miss out not just on school, but outings with friends, plans with the family, and even normal activities like church and going to the store. They want to be in school, they want to be with their friends, they want to be a normal child who can make plans and keep them. They want to be healthy!

### **When A Parent Has ME/CFS and/or FMS, Too**

Doctors and patient advocacy organisations often hear from families who are struggling to cope with at least two, and sometimes, more people with ME/CFS and/or FMS. Especially tragic are the situations where a parent and child share the same illness. Special understanding and sensitivity are required from teachers working with a child with ME/CFS and/or FMS who also has an ill parent. We have already discussed how having an ill child can affect one's family life. Now add to that scenario the presence of a parent who is also disabled with ME/CFS and/or FMS. Remember that adults have the same symptoms as children: extraordinary fatigability, constant pain, difficulty concentrating and remembering details, and other symptoms. The traditional expectations of parents as partners in their child's education may need to be modified, just as the child's curriculum may need to be modified. One mother with ME reported:

When my daughter was struggling to keep up with her schoolwork because she missed so many classes, we had frequent meetings with the counsellor. There was clearly the expectation that I, the mother, would be able to sit at the table in the evening with my daughter, helping her catch up missed schoolwork. What I had trouble getting across was that, no matter how well I might appear to be in the counsellor's office and even if I rested all day to save energy, I could never predict how I would be feeling, and functioning, in the evening. Many nights I had to crawl up to bed long before my children did, and toss and turn in agony, with my head buzzing and spinning, until I fell asleep. And what was my husband doing? He was working nights to earn the income lost because I was disabled. And, on the nights

when I was able to sit up and help my daughter with her work, it turned out that my math skills were now way behind hers even though I had studied calculus at university.

All parents are emotionally involved when it comes to their children and, particularly, when they feel that their children have needs that should be met. When teachers remember that there can be emotional symptoms of ME/CFS and/or FMS, they can feel more sympathetic towards ill parents who may be weepy or angry in discussions about their children's education. Parents with ME/CFS and/or FMS may be 'emotional' for other reasons as well. They may become more frustrated by difficulties obtaining services for their children because they are already so exhausted and worried, and often because they also have experienced a tremendous struggle to obtain a diagnosis and accommodations in the family, in educational settings and at work.

When you, the teacher, remember that these parents have been living the double nightmare of illness in themselves and in their children, your empathy and support will go a long way. If you can also show a commitment to providing the education that the children of these parents deserve, you can also bring a spark of hope and joy into their lives. Nothing is more nourishing to the spirits of parents than seeing their children get "a better deal" than they have had! Knowing that they have had an impact on the system through helping their child, and that what they have accomplished may help many other children, gives meaning to lives that are often filled with sorrow.

### **Points for Teachers**

Teachers, educators, what can you do when working with parents and children with ME/CFS and/or FMS in educational planning? Listen! Listen to them! Listen to your students, to their families, to what they say they want and what they need. Take into account the challenges that they face when battling ME/CFS and/or FMS. Consider the long journey they have been on and will most likely be on for a while. These are children that want to learn, want to succeed, want to find a way to connect with their peers. Understand their journey by talking to them and finding a way to make their wishes for workable academic plans a reality.

The last words in this Sourcebook go to a mother who is a teacher herself. The following account, and others like it, makes us proud of our schools and our teachers.

**Jacob** (submitted by his mother):

Jacob missed 35 to 40 days per year in primary school. By the end of Grade 7 he became much worse and missed May and June of that year and the entire Grade 8 year. He managed to get his Grade 8 year by me tutoring him and eventually a school board tutor for one hour a day for arts subjects.

In high school he has always carried a reduced load and has missed 25% of his classes. In the first two years we met with the teacher and a guidance teacher at the beginning of each semester to explain his illness and to explain the techniques that worked to keep him in school and to keep him up-to-date with classes. We always emphasised that we didn't expect a lot of extra work from the teachers - just co-operation with giving us work during absences of 2 days, postponed tests, etc. For the past 4 semesters I have only sent letters to the teachers.

We have had wonderful co-operation from all the staff. I think the intense advocacy, plus the teachers getting to know Jacob and realising his problems were legitimate and that he was trying, helped a lot.

We are not surprised that Jacob's teachers were so helpful. We know that Canadian educators are dedicated and compassionate professionals who recognise that every child has a right to be educated. As we say goodbye, we want to thank you for your dedication to our children. At the National ME/FM Action Network, we look forward to forming strong partnerships with educators as we work together to serve the best interests of young people with ME/CFS and/or FMS.

## Appendix 1

### Functional Ability Scale for Children and Young People With M.E.

By

**Jill Moss**

Association of Young People with M.E. (AYME)

*(This Functional Ability Scale is published with the kind permission of Jill Moss.)*

#### **Functional Ability Scale for children and Young People with ME**

When using this scale it is important to remember that:

- Flexibility in its use will help all concerned
- There is no predictable pattern to M.E.
- Many may fall between each noted percentage
- Fluctuations will occur over short periods of time

#### **Flexibility**

This scale should be viewed flexibly; used to assist children and young people to pick that which best describes their functional ability level. It is important for them to have significant input into their own chart, thus increasing personal control over their illness. It may be that a young person is at a different point on the scale regarding their mental functioning from their physical ability. Clinicians and carers should not view 50% ability as meaning, for example, that a patient is able to walk half the distance of a healthy person. Terms such as 'part-time' should be viewed as a 'few hours', but only the child or young person will really know how much is right for them.

#### **Predictable Pattern**

It should not be assumed that movement on the scale means the beginning of a continued downward slide or continued improvement. Young people can make sudden, large jumps, or become stable at one level for a time and then make a sudden or gradual move in either direction. Large increases are not, necessarily, indicative of 'being over ME'. Careful and supportive management, with the young patients being able to pace themselves in a way that is most comfortable to them, will see improvement over time. It may take many days to recover from an activity, mental or physical, that pushes them beyond their capability.

#### **Falling between scales**

Young people may find themselves as falling between the noted points on the scale. They should be encouraged to fit in their own wording that matches their present capacity and functioning.

#### **Fluctuations**

Fluctuations on the scale may occur, with variations often seen over single days or weeks, especially if the young patient is expected to do more than can be managed with ease. It may be useful to note the point on the scale on a 'good day' as well as a 'bad day'.

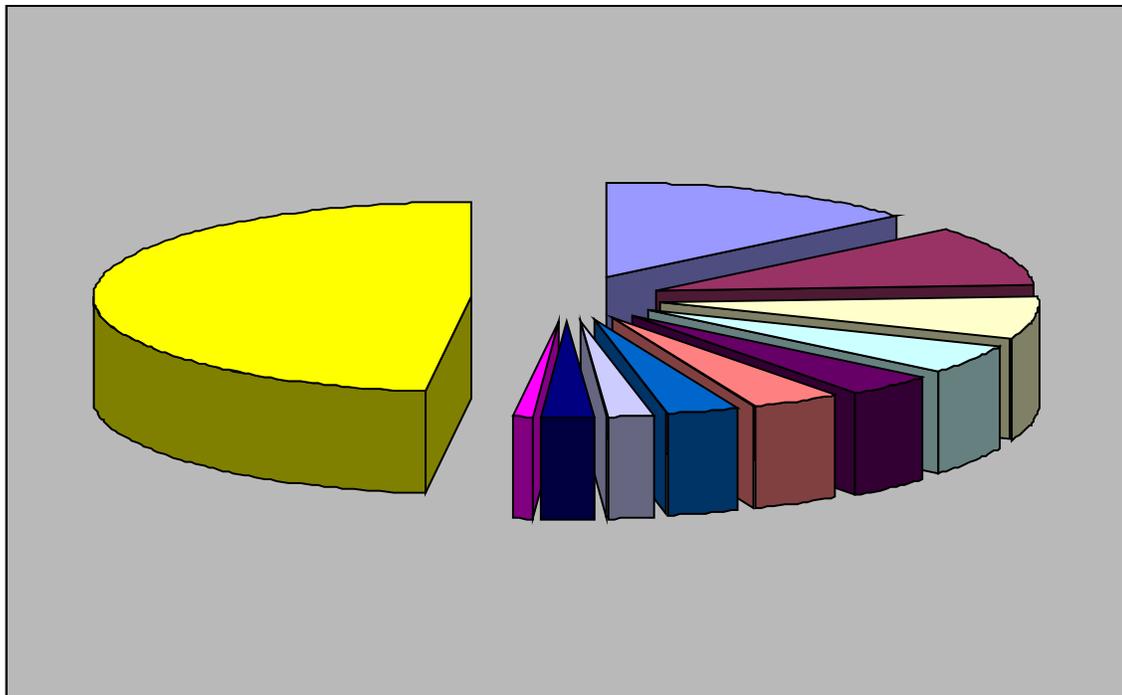
## Symptoms

*Symptoms most regularly felt by young people are charted by Bell\*1 [1995] –*

Fatigue; Headache; Neurological disturbance [dizziness, disturbed balance, difficulty with concentration, poor temperature control, etc]; Sleep disturbance; Eye pain; Muscle pain; Abdominal Pain; Depression; Joint pain; Painful glands.

These symptoms are extremely varied, both in terms of their severity and those present. A study carried out by AYME and the Open University\*2, entitled 'Speaking Up', asked over 500 children and young people with ME, to rate these symptoms on a scale between 0 [no symptom felt] and 10 [symptom very severe]. 1 – 3 was considered a 'mild symptom'; 4 – 7 a 'moderate symptom'; 8 – 10 a 'severe symptom'.

Symptoms that were given the highest rating from each person were noted [see table below]  
52% rated one symptom more severe than others,  
48% rated two or more symptoms equally severe.



Those children and young people who marked one symptom as being more severe than others, rated in the following percentage e.g. 10% rated headache as their most severe symptom:

Fatigue	14%	Muscle pain	4%
Headache	10%	Abdominal Pain	3%
Neurological disturbance	7%	Depression	2%
Sleep disturbance	5%	Joint pain	2%
Eye pain	4%	Painful glands	1%

Most of these symptoms are felt at some point – often constantly up to around 60-70% ability. Fatigue must always be present for a diagnosis but it is not always the worse symptom (*Speaking Up*. AYME/OU 2000 \*2).

AYME Functional Ability Scale – original scale published in *Somebody Help ME* (1995\*3) by Jill Moss

### **Fully Recovered**

**100%** No symptoms even following physical or mental activity. Able to study and work full time without difficulty, plus enjoy a social life.

### **Virtually Recovered**

**95%** No symptoms at rest. Mild symptoms following physical or mental activity - tire rather easily but fully recovered next day. Able to study or work full time without difficulty but a slight restriction on social life.

### **Mildly Affected**

**90%** No symptoms at rest. Mild symptoms following physical or mental activity - tire easily. Study/work full time with some difficulty. Social life rather restricted with gradual recovery over 2/3 days.

**80%** Mild symptoms at rest, worsened to moderate by physical or mental activity. Full-time study at school/ college is difficult, as is full-time work, especially if it is a crowded, noisy or busy environment. Home tutoring or part-time study without difficulty.

### **Moderately Affected**

**70%** Mild symptoms at rest, worsened to severe by physical or mental activity. Daily activity limited. Part time study at school/college is very tiring, and may be restricting social life. Part time work may be possible for a few hours in the day. With careful pacing out of activities and rest periods, one may discover windows of time during the day when one feels significantly better. Gentle walking or swimming can be beneficial.

**60%** Mild to moderate symptoms at rest. Increasing symptoms following physical or mental activity. Daily activity very limited. Study with others or work outside the home very difficult unless additional support is available, e.g. use of a wheelchair/quiet room for a rest period. Short (1-2 hours) daily home study/work may be possible on good days. Quiet, non-active social life possible.

### **Moderate to Severely Affected**

**50%** Moderate symptoms at rest. Increasing symptoms following physical or mental activity. Mid-day rest may still be needed. Simple, short (1hr) home study/home activity possible, when alternated with quiet, non-active social life. Concentration is limited. Not confined to the house but may be unable to walk without support, much beyond 100/200m. May manage a trip to the shops in the wheelchair.

**40%** Moderate to severe symptoms following any activity. Care must be taken not to over-do one's life style at this stage. Not confined to the house but unable to walk much more than 50/100m, usually requiring aids such as walking stick/crutches. May manage a wheelchair trip to the shops on a quiet day. Requires 3 or 4 regular rest periods during the day. Only one 'large'

activity possible per day - friend dropping by or doctor's visit or short home study (half hour at a time) etc – with space usually requiring rest day/s between.

### **Severely Affected**

**30%** Moderate to severe symptoms at rest. Severe symptoms following any physical or mental activity. Usually confined to the house but may occasionally take a quiet wheelchair ride or very short, gentle walk in the fresh air. Most of the day resting. Very small tasks possible but mental concentration poor and home study difficult. As mentioned in the report on ME to the Chief Medical Officer, (2002\*4) and the DfES report on education for children with medical needs (2001\*5), children may be too ill to access any education at all. This should be respected and kept under review.

**20%** Fairly severe symptoms at rest. Weakness in hands, arms or legs may be restricting movement. Unable to leave the house except very rarely. Confined to bed/settee most of the day but able to sit in a chair for a few, short periods. Unable to concentrate for more than one hour a day but can read for about 5-10 minutes at a time.

### **Very Severely Affected**

**10%** Severe symptoms following any activity. Weakness and pain in arms or legs. In bed the majority of the time but feeling more stable and less dizzy. No travel outside the house. Concentration very difficult indeed. A friend can be seen for ten minutes or so.

**5%** Severe symptoms almost continuously but may be possible to be propped up in bed for very short periods. Weakness and pain in arms or legs can give rise to paralysis; dizziness and nausea. Small, personal care may be possible (e.g. if washing equipment placed on the bed it may be possible to wash some parts of the body). As with 0%, sudden jerking movements can be a problem and what may be described as panic attacks are felt. No TV is possible but a little quiet music or audio book may be listened to for a few minutes. A friend can be seen for a minute for a hug and a few words.

**0%** Severe symptoms on a continuous basis. In bed constantly, feeling extremely ill even with permanent rest. Severe dizziness makes it almost impossible to be propped up in bed for longer than a few minutes at a time. Light and noise are very painful to the eyes and ears – curtains are closed and earplugs are needed. Severe pain almost anywhere in the body with the skin feeling very cold and extremely sensitive to touch. Unable to care for oneself at all; washing needs to be done a tiny bit at times throughout the day. Nausea and severe fatigue make eating extremely difficult. Liquid based food preferred – little and often. Occasionally, nasal feeding tubes are required when the energy to chew is completely spent. Any stimulus worsens the feeling of being severely ill, with no movement in the bedroom preferred. Any visitor to the room is almost impossible. Talking, even to the carer/family, is often impossible. This is often misread as being 'selective mute'. Severe adrenaline rushes felt with heightened sensitivity; jumping and over reacting to doors shutting/door bell ringing, etc. Sleep pattern often completely reversed.



President: Esther Rantzen OBE

*This functional ability scale was originally devised by AYME's founder, Jill Moss in 1995\*3. In 2001/2, responding to principles laid down in a report called 'The Expert Patient' (2001\*5) the scale was distributed to a random 20% of AYME's members for comments and suggestions on re-drafting. The scale overleaf represents the views of our expert patients in charting the progression of their illness and the varying functional ability levels contained within. The newly completed scale was validated by a different group of members, who commented on its face, content and predictive validity; 90% rating it "useful and workable". It is presently being offered for journal publication.*

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The Association of Young People with ME [AYME] is a national, award winning charity dedicated to providing cheerful support, advice and information to children and young people between the ages of 5 and 25, and their families. It is a membership organisation - free to join – which allows disadvantaged young voices to be heard, and information to be shared. Personal and electronic contacts are made through the members' own On-line and Membership teams, allowing peer groups to be formed which rebuild self-confidence. The General Services team ensures that all members receive a birthday card and small gift on their special day, and have access to a comprehensive, postal library of books, tapes and videos, available for free hire. Special attention is given to the needs of our severely affected members and our children under 12 years. There is an opportunity given to young people who are well enough, to take an active part in the running of their organisation from their own homes, building confidence and self-worth, adding skills to their CV in an alternative and unique way from their healthy peers. In the words of one of our volunteer members: "AYME is like a big family, club and workplace, all rolled into one. You can be anything you want in AYME".

Further information about ME and AYME can be obtained from; AYME Ltd, Box 605, Milton Keynes, MK2 2XD. Tel: 01908 373300 Fax 01908 274136 email: [info@ayme.org.uk](mailto:info@ayme.org.uk)  
<http://www.ayme.org.uk/>

## Appendix 2

### Resources

#### Books

*Guidelines For Schools: Understanding And Accommodating CFIDS/FMS Chronic Fatigue And Immune Dysfunction Syndrome And Fibromyalgia Syndrome*

Contact: The National CFIDS Foundation, 103 Aletha Rd, Needham Ma 02492

Tel. (781) 449-3535 Fax (781) 449-8606 <http://www.ncf-net.org/general/guidlines.htm>

*Guidelines for Schools*, edited by Jane Colby.

Email [jane@youngactiononline.com](mailto:jane@youngactiononline.com) or [Jane@jafc.demon.co.uk](mailto:Jane@jafc.demon.co.uk)

<http://www.youngactiononline.com/docs/guide.htm> Contact: Jane Colby at: +44 1245 401080

*Zoe's Win*, by Jane Colby. Published by Dome Vision. ISBN 0953733009. It can be ordered from Young Action Online, PO Box 4347, Stock, Ingatstone, CM4 9TE.

*A Parent's Guide To CFIDS: How to Be an Advocate for Your Child with Chronic Fatigue Immune Dysfunction Syndrome*, by David S. Bell, Mary Z. Robinson, Jean Pollard, Tom Robinson, Bonnie Floyd. Available from the CFIDS Association of America; call 704-365-2343 to order. The price is \$18 plus \$4 shipping & handling.

#### Websites

**National ME/FM Action Network of Canada – Youth Site:**

<http://www.mefmaction.net> The Youth Site provides information to assist families and educators of young people with ME/CFS and FMS. There is also a “Young Writer’s Club” where poems and short stories by young people with ME/CFS and FMS are posted.

**The Pediatric Network for Chronic Fatigue Syndrome, Fibromyalgia and Orthostatic Intolerance:** <http://www.pediatricnetwork.org> This website and forum is dedicated to issues that families of children with these illnesses face, and has an online support group with more than 300 members.

**Lyndonville News:** <http://www.davidsbell.com> The “Lyndonville News” is the website of Dr. David S. Bell, a world authority on ME/CFS, FMS and OI in young people.

**Young Action Online:** <http://www.youngactiononline.com> is an U.K. website for information on ME/CFS in young people.

**AYME:** <http://www.ayme.org.uk/> provides support, advice and information to children and young people between the ages of 5 and 25, and their families.

**The CFIDS Association of America, Youth Pages:** <http://www.cfids.org>

## Appendix 3

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