

## For months *and months!*...

- barely finding the energy to feed and dress yourself; too weak to do the slightest thing, no matter how much you want to;
- unable to get enough sleep or waking up from a long night's rest feeling like you hardly slept at all;
- living with your head in a fog, unable to concentrate, your memory like a sieve;
- muscles and bones aching all over, the intensity varying, but often so strong that you feel like you've been run over by a truck;
- headaches unlike any you've experienced before, that have a different pattern or intensity;
- feeling like you have a permanent case of the flu;
- being **totally** incapacitated for hours or days after exertions that you used to think nothing of;
- unable to count on feeling reasonably well a week ahead, even if you've felt OK for the last few days, since your energy fluctuates without rhyme or reason.

Nonetheless from time to time, you look healthy!!! It's puzzling to those around us.

## That's what the first year (maybe the first of many years) of ME/CFS is like.

And, generally, these symptoms emerge overnight, following a viral infection, a hormonal imbalance of some kind (pregnancy, prolonged stress, etc.), exposure to toxic substances, or from some other "trigger". [5]

**But, I ask you!**  
**What is wrong with me?!**

## Many parts of you are out of order notably the immune, endocrine and neurological systems.

Recent research undertaken all over the globe suggests the existence of biochemical or molecular dysfunctions that can be activated by various "trigger" events in people who have a genetic predisposition. [6]

We're starting to understand the underlying mechanisms: the chain reactions of malfunctions that affect the biochemistry of the body at many levels and that might explain the multiplicity of seemingly disparate symptoms of CFS. [7]

For now, diagnosis is long and arduous because it involves a long process of elimination, but researchers are constantly exploring promising avenues for **diagnosis** and **treatment**. [8]

## When your body is out of order, your life is upside-down!

- the slightest activities, even light and enjoyable ones, require an effort;
- slightly demanding or more intense activities, whether physical, intellectual or social, produce unpleasant after-effects;
- you cannot commit to engagements ahead of time because you can't predict how your fluctuating energy levels will make you feel;
- because of cognitive difficulties and low or unpredictable energy levels, you are forced to **greatly restrict** your activities: work / study, housework, family, social events, etc.;
- you must maintain a balance of activities and rest periods within short blocks of time, which often conflicts with the rhythms of modern life;
- your loved ones are affected; they can have difficulty understanding, and can lack compassion;

- you bounce from doctor to doctor, from test to test to find out what's wrong and try to fix it;
- employers and insurers make it difficult for you to get time off, and it can be difficult to get services from CLSCs;
- your earnings are reduced while your healthcare and other related expenses (housekeeping, for example) can increase enormously.

On top of all this, you find yourself suffering in isolation, barely able to keep your spirits up.

## In short... *it's rough!!!*

Battling CFS is like having to face a brutal enemy who is larger and stronger than you. You must therefore develop a strategic plan of action. [9]

You need determination, courage and patience just to be able to **withstand** all of these symptoms, then you must learn to **improve your condition** and live as full a life as possible – and **be happy** – within the bounds of your limitations.

## And how will this all turn out?

Generally, CFS evolves as a series of **periodical setbacks and improvements** that are more or less severe and prolonged, spread out over several years. It appears that the prognosis is better for children. [10]

- You can promote an overall improvement in your health by adopting a disciplined lifestyle (balancing activities and stress, limiting physical activities, good sleeping habits, healthy eating, etc.). [8, 9]
- Generally, after a bit of experimentation, you should be able to identify the medications or other treatments that help diminish your symptoms to a greater or lesser degree. [8, 9]

Even in cases where a patient has been "healed", there are still lingering after-effects and limitations, so you must **live your life differently** than you did before your encounter with **ME/CFS... ME/CFS... ME/CFS... ME/CFS...**

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Prepared by Cécile D'Amour (April, 2002)

**General sources** : documents from health organizations; conferences, articles and other documents from doctors; AQEM documents and documents from other CFS organizations; patient case histories; my own extensive experience with CFS.

### Specific sources :

[1] Québec population estimates for 2001 from Statistics Canada: 7,410,500. Likely prevalence of CFS in Québec: on the order of 4 per 1,000 population, based on the estimated prevalence for the USA of 422 per 100,000 population, according to L.A. Jason and colleagues at DePaul University in Chicago (Arc. Int. Med. 1999; 159 (18); pp. 2129-2137). According to other studies, the prevalence is much higher, up to 740 per 100,000 population (in the Introduction to the work of Englebienne and his collaborators; they also state that CFS reports are increasingly prevalent).

[2] Englebienne P. and K. De Meirleir (ed.), "CFS – A Biological Approach", CRC Press, 2002, 291 p., Foreword

[3] (I cannot find the references for boys / girls)

[4] Englebienne P. *et al.*, Introduction

[5] Englebienne P. *et al.*, p. 213-215

[6] Englebienne P. *et al.*, Foreword

[7] Englebienne P. *et al.*; Chapters 4 to 8; particularly Section 8.4: "Onset, Immune Changes, and Infection – An Integrated Model that Explains the Symptoms of CFS" ; also see Section 10.2: "Etiology, Pathogenesis, and Evolution of CFS: Laboratory Perspective".

[8] Englebienne P. *et al.*; Chapters 9 and 10; Section 10.3, for strategies of diagnosis.

[9] Dr Charles W. Lapp. "The Treatment of CFS. The Perspective of a Private Specialty Practice in Charlotte, North Carolina", conference, April 1997, cf. AQEM site.

[10] Englebienne *et al.*, Introduction; they indicate a study in which 76% of children were completely cured.

### **Information and support: giving... or receiving**

**AQEM** (Association québécoise  
de l'encéphalomyélite myalgique ou SFC)

1671, Henri-Bourassa Blvd. East, Room 4  
Montréal, H2C 1J4

(514) 369-1689 or 1 (877) 369-1689

[www.aqem.quebec.com/aqem](http://www.aqem.quebec.com/aqem)

## **Recognition of ME/CFS, a syndrome with many names and faces**

In June of 1998, the *Collège des médecins du Québec* published guidelines on the subject of "Chronic Fatigue Syndrome", adopting the name and 1994 definition from the Centers for Disease Control and Prevention in the United States, revised from a definition first adopted in 1988, which lasted less than 15 years.

This syndrome is now **recognized internationally by health organizations**.

Even though marked interest in CFS dates from the mid-1980's, several medical publications suggest that this syndrome is not a new phenomenon, since cases (as far as we can tell) have been reported throughout the last few centuries. [4]

The syndrome known in Québec as CFS is also known by **several other names**, including "Myalgic Encephalomyelitis" (in Canada and the United Kingdom), "Immune Deficiency Syndrome", "Chronic Fatigue and Immune Deficiency Syndrome" and "Natural Killer Deficit Syndrome".

Each name emphasizes one or other aspects of the problem. No matter which name you use, this syndrome consists of **multiple symptoms of varying types** (immunological, neurological, endocrinological, neuro-psychological, musculoskeletal, etc.) of **prolonged duration**. Furthermore, these symptoms describe conditions that can fluctuate over time for one individual, and that can also vary from one person to another.

## **ME/CFS Myalgic Encephalomyelitis / Chronic Fatigue Syndrome**

**When your body  
is out of order,**

***your life is  
upside-down!***

In Québec, about 30,000 people [1] of all ages, ethnic, and socio-economic groups [2] are afflicted with ME/CFS. Among those stricken with ME/CFS after reaching puberty, roughly three quarters are women. In children, the proportion of boys to girls is about even. [3]

**Thousands of people  
affected over many years!**

***Thank you!  
For taking a few  
minutes  
to understand.***