

Chronic fatigue syndrome

(Myalgic encephalomyelitis)



Understanding the illness

This brochure is intended for the friends and family of those living with chronic fatigue syndrome (CFS) and anyone else who would like to know more about the illness. It aims to provide more information about CFS and its related problems.



Chronic fatigue syndrome strikes indiscriminately

Mélanie, 28 years old, has lived with CFS for four years; she is single, and a former international trade representative now on welfare. *Symptoms:* sudden loss of energy, severe weight loss and loss of balance. *Consequences:* loss of employment and friends, guilt feelings and withdrawal. *Treatments favoured by Mélanie:* consultations with her physician and medication.

Sarah, 42 years old, has lived with CFS for three years; married and a mother of two children, she used to work as a freelance translator. *Symptoms:* overwhelming fatigue, hypersensitivity to noise. *Consequences:* loss of autonomy, frustration towards physicians' lack of recognition for her condition. *Treatments favoured by Sarah:* massage therapy and alternative medicine.

Jacques, 50 years old, has lived with CFS for 20 years; he is divorced, and formerly employed as building manager. *Symptoms:* muscle pain and lack of energy. *Consequences:* stress, anxiety and insecurity feelings. *Treatments favoured by Jacques:* monitoring energy levels, moderate physical exercise and participating in support groups.





What is chronic fatigue syndrome?

Chronic fatigue syndrome (CFS), also known as myalgic encephalomyelitis (ME), is a neurological disease recognized by the World Health Organization. It is characterized by prolonged fatigue that interferes with day-to-day activities. The condition can develop suddenly in otherwise healthy people, and its exact cause may never be clearly determined. However, an association has been shown between certain types of infection (mostly caused by viruses) and the onset of CFS.

Contrary to popular belief, CFS is a genuine illness. It is not only 'in the heads' of the people who suffer from it.

Even though CFS is rather common, it remains little known. Currently, we do not have accurate data on the number of people with CFS in the province of Québec, but according to data collected in 2007 by Statistics Canada, up to 1.5% of the population could be affected.

The disease is not easily apparent to others. Symptoms can resemble those of other illnesses, such as multiple sclerosis, heart disease, neurological disease, mental illness, depression or cancer. A diagnosis of CFS can only be made after all other possible causes have been ruled out.

Diagnosing CFS can be difficult and time-consuming, as clinicians have to perform numerous tests in order to confirm the presence of the illness.



What are the main symptoms?

It's difficult to describe how one feels. It's not the same type of tiredness as after exertion. It's a type of tiredness... It's an uncomfortable tiredness. It's as if I hadn't slept for 48 hours...

CFS hit Mélanie without warning four years ago. One evening, after a long day at work, she suddenly felt completely drained of energy. Even after resting, her condition did not improve. Now, exhaustion is part of her daily life. Mélanie lost her job. Her friends drifted away, unable to understand her condition. And even though she knows that she suffers from a real disease, she sometimes feels responsible for her situation.

CFS symptoms are not easy to describe. They are not limited to a feeling of extreme fatigue, and can vary from one person to another.

Here are the most common symptoms:

- Extreme and prolonged fatigue, not relieved by resting, that has lasted at least six months
- Memory and concentration problems
- Headaches
- Sore throat
- Muscle and joint pain
- Dizziness
- Sensitivity to noise, odours and visual stimuli
- Anxiety and irritability
- Feeling of malaise in the muscles lasting more than 24 hours following physical exertion
- Sleep disorder
- Etc.

The feeling of extreme exhaustion, lasting more than six consecutive months, is not necessarily the result of physical or intellectual exertion and is not relieved with rest. Exhaustion can be accompanied by memory and concentration problems, muscle and joint pain, headaches or a feeling of malaise that is still present 24 hours after physical or mental activity that was easily tolerated before the onset of CFS.



What is the impact of CFS on daily life and on interpersonal relationships?

Even though the exact causes of CFS are not yet known, many studies have managed to explain a big part of the all-too-real ailments that affect people living with the disease. These symptoms can turn simple gestures of daily life into difficult challenges.

Physical and psychological problems caused by CFS can eventually lead to considerable losses. People with more severe symptoms are not fit to work or to take on any family responsibilities, and may even lose their autonomy. They may become dependent upon a spouse or a family member, which can lead to stress, guilt and frustration.

Sometimes, people with CFS may express feelings of frustration toward the people with whom they interact. This frustration can stem from comments and actions that are perceived as insensitive, distasteful or offensive, and seen as criticism. With time, people living with CFS can become distrustful and be constantly on the defensive when asked about their health.

Naturally, the development of dependency to others coupled with disbelief from a person's social circle can have a significant emotional impact on people living with CFS. The gradual loss of functional capacity, both at home and at work, may also be a source of prejudice and contribute to isolating the person, sometimes with dramatic consequences.



The emotional burden

Mélanie: *In January 2006, I quit my job, which was extremely painful for me because I loved what I was doing. I really liked it. My weight dropped to 100 pounds, and I slept three hours a night and had pain all over. I didn't know that it was [CFS], but it was obvious that I couldn't go on.*

Several negative emotions can appear following painful events such as losing one's job. On top of the revenue loss and the impact on their quality of life, people living with CFS can develop feelings of guilt. And even though most people with CFS who had to leave their jobs are still hoping to get back to work, they are often afraid they will not be up to the task.

Symptoms that change constantly and unpredictably can give people living with CFS the feeling that their body is a stranger, different from the one they had before. Since they cannot be as active as they used to, they tend to feel less useful, and this can initiate a vicious circle. Worries, anxiety, guilt and hopelessness can sometimes lead to depression and even suicidal ideation and behaviour in some cases.





Prejudice and isolation

Jacques: *It's one of the worst aspects...other people. The lack of understanding, the judgment of others. He saw that I was sick. 'It's all in your head,' my boss would often say. [...] In his eyes, I was crazy. That was hard. People I was friends with and who I worked with also abandoned me.*

The lack of knowledge about CFS often results in close ones and health professionals suspecting mental illness or malingering (simulating illness). Not only does this add to the frustration and anxiety felt by people living with CFS, it also leads to worse prejudice from others and further isolation.

Sarah: *I go to the hospital for some tests and when I tell the specialist that I suffer from chronic fatigue, she says 'Ah! Chronic fatigue!' and rolls her eyes... Even the specialist doesn't believe it's real and tells me to my face. It's insulting and contemptuous.*

Health professionals can also be misinformed about CFS. The people who suffer from the disease are filled with shame when confronted with the incredulity expressed by some clinicians. They are made to feel like their condition is not serious. Without the recognition of their condition as a disease by health professionals, the persons affected are left feeling confused and painfully rejected. Some sceptical physicians tend to believe the disease is imaginary and will refer patients to psychiatrists. It is important to understand that the emotional problems that stem from the disease are not actually causing it. CFS is not an imaginary disease; it is a genuine illness.



Support from the social circle

Living each day with CFS requires a lot of courage, so the support and understanding of close relations are all the more necessary to the affected person's well-being.

Although the disease can become overwhelming for a lot of people living with CFS, not all people with the illness lose their autonomy or develop a disability. Adjustments to the pace and quantity of work can help them stay active, contribute to their self-esteem and prevent isolation.

Even parents and friends can sometimes feel like they're running out of steam. However, their ability to listen, their understanding and their support during difficult times can be invaluable in helping to deal with feelings of anxiety and isolation. They can help people living with CFS to better adapt to their situation and even to go back to a more active life that they can handle.

References

This brochure is based on a report published by the Agence d'évaluation des technologies et des modes d'intervention en santé (now the Institut national d'excellence en santé et en services sociaux, or INESSS). It is based on information and testimonies gathered as part of the Agence's scientific study of people living with chronic fatigue syndrome.

SOURCE DOCUMENTS:

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2 Rouleau, Guylaine, Ugo Ceppi, Vibe Hjelholt Pedersen and Pierre Dagenais. Le syndrome de fatigue chronique — État des connaissances et évaluation des modes d'intervention au Québec. Montréal, QC: Agence d'évaluation des technologies et des modes d'intervention en santé (AETMIS), 2010.

USEFUL LINK: Association québécoise de l'encéphalomyélite myalgique www.aqem.org

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