



## PRICE OF MYALGIC ENCEPHALOMYELITIS

by Wendy Boutilier

**W**ithout a doubt, the physical price of Myalgic Encephalomyelitis (ME) is devastating. However, the physical price of ME is not what sets the illness apart. Physical loss is just one side of the coin. Unlike other illnesses, ME carries an additional burden.

Because the illness is poorly understood, because it is often called Chronic Fatigue Syndrome which sounds trivial, and because many who suffer from ME appear to have no physical signs of disease, they face the illness under a wave of public skepticism and misinformation.

Unlike other diseases, Myalgic Encephalomyelitis can be an illness where sufferers go without support from their communities, their governments, and their family. Family, career, friends, community and the medical system are key to enduring a chronic illness. For those with ME, these typical supports are often skeptical, disinterested, and nonexistent. As such, ME cuts a deep swath, producing not only suffering and stealing life's dreams, but also destroying family and friendships.

At the root of the problem is lack of information. Many health care providers receive information on ME that is often incomplete, inaccurate, or politically-charged. Other times, they receive no information about research findings related to ME. Research on low molecular weight cell RNase L (and antiviral molecule), red blood cell abnormalities, low circulating blood volume, and genetic



profiling has been able to elucidate a unique path physiology for subtypes of sufferers with Myalgic Encephalomyelitis (ME). Yet, many clinicians are unaware of this research.

Despite these advances, ME has remained frozen in political limbo. Government agencies often propagate misleading information on ME as a “fatiguing illness”, perpetuating public apathy. The definition of ME has been broadened a handful of times, bringing less disabled subjects into ME research and affecting public perception even more. For years, psychiatrists have received government funding to question the “perceptions”, “attributions”, and “perpetuating behaviors” of the predominantly female ME patient population. Many who should be working to help those with ME, instead work to diligently portray ME as an illness of simple de-conditioning and “avoidance”, and they make every opportunity to advance their views among the public – with government committees, research definitions, and agencies as their key battlegrounds.

*Even the name has played a role. A growing number of researchers have begun to question the societal, gender, and sociological factors that are behind both professional and public attitudes toward Myalgic Encephalomyelitis (ME). It has been redefined as Chronic Fatigue Syndrome (CFS) and worse Yuppie Flu. According to a ME researcher, bias, a stigmatizing name, and public mis-perceptions are keeping the illness from advancing. Researchers speak candidly about ME: "This disease... is actually more debilitating than just about any other medical problem in the world. Nevertheless, most accounts of the illness have simply shortened its name to the flip and damaging misnomer "chronic fatigue", as if ME is a mild inconvenience."*

The lives of those with Myalgic Encephalomyelitis confirm this bleak assessment. It doesn't take long to realize that those with ME face a different burden. From Sea Biscuit author Laura Hillenbrand, to a biologist disabled by ME, to a wife unable to take care of her children, the stories begin to sound familiar: “I lost my health; I lost my family; I lost my job; I entered poverty; I faced a new isolating and impoverished reality”. The physical price is only the starting point for the price of ME. ME robs so much more. It isolates.

Dreams dashed. Hopes stolen. The battle with ME is often fought alone. When a sufferer speaks of ME, they speak of more than physical challenges.

“In my youth I had gone to school, chose a career and had just begun my own business when I became ill in 2008. By 2010, I was completely disabled. Before this, I had been working 60 hour weeks with energy, health and optimism, type A personality.

I expected my life would include working until retiring, but the illness has destroyed my expectations and most of the things in life one takes for granted, caused me to become dependent...

*It is so sad to realize I am unable to make plans, even a day in advance; there are no dinners with friends, no saving for travel. The illness is oppressive, painful, boring & lonely. For many, it has caused a frightening financial situation in the present and a dismal outlook for the future because tragically, there is no end in sight.*

Often an illness can solidify family ties, causing the family to rally around the sufferer. However, because many family members are misinformed about Myalgic Encephalomyelitis, family relationships of those with ME are often lost. “Other illnesses show on the face or body that you are ill, too many times I hear "OH you look so well" I want to say, you have no idea what it took to get here, but in reality we do look good. It is a disease of deception. I have experienced profound loss. It is one day at a time and very sad. I think if others could understand it would be easier to find a way to live with this and doctors who will understand.”

The safety net provided to sufferers of illnesses can often fail those with ME. Many insurers have decided it makes good business sense to question the validity of those who are diagnosed with the illness. In 1993, less than 500 people in the U.S. was approved for disability with ME, and illness of



over 800,000 sufferers. By 2002, this figure had changed very little. I am fortunate that mine was recognized due to a documented bout of Necrotizing Fasciitis in December 2008. I am a medical oddity by surviving a mortality rate of 76% only to inherit ME. My disability pension came wrapped in gold but for others obtaining disability is a nightmare.

*Many people with ME are falling through the cracks of the government safety net. One sufferer talks of huddling down in a frozen, small apartment, lights and heat off, shivering under the covers. Once a successful individual who ran a multi-million dollar company, life has come full circle. Today, he lives without access to needed health care.*

Another lost his financial future to ME. Watching bills pile up. "I worked in a biopharmaceutical company. In financial terms, I have lost (I estimate) a minimum of \$200,000 in earnings, and more probably over \$1 million as I would have been promoted and/or taken higher-paying jobs. I have also had \$150,000 in medical expenses and \$250,000 in medical-related expenses." A recent study estimated the cost of Myalgic Encephalomyelitis (ME) in the United States at 9 billion dollars, most of which is born by those with the illness and their families.

There is another cost of ME. Many people with ME describe a longing, a hunger to return to the activities they used to enjoy. A 50 yr old woman with ME who lives in Ontario Canada, says: "Immediately before I was disabled I spent pretty much seven days a week at the office my husband and I were employed. Mostly, I did office work, and anything else that needed attention or that other staff needed help with. Now, physically, I exhaust too readily, and the pain level keeps me from many of my former activities... many jobs and hobbies had to be shelved."

A 30 yr old experienced a similar story, her career path was completely altered: "I was a production supervisor at a small factory, a part time (on-call) CNA, and a part time nursing student (2nd year). I have lost my ability to work or continue to attend school plus many activities of leisure I enjoyed".

## **A Disease Designed Like a Prison.**

Most are realistic about where Myalgic Encephalomyelitis (ME) stands, politically, publicly, and sociologically. They understand the public's skepticism has multifaceted causes. Sociological attitudes, gender attitudes, a stigmatizing name, the medical and clinical community's, a broad amorphous research definition all play a role in the struggles they face. ME is an often political and sociological battleground; one they realize they are losing.

Yet behind all of the controversy and politics is a human element; people with ME feel deeply. They miss and long for the freedom to be, to become, and to live. An anonymous ME sufferer says it best, "There were so many things I enjoyed doing before that I cannot do now. Horseback riding, painting, writing, dancing, swimming -- too many to even think about at the moment. I had a very hard time being stuck in the house... How does one change oneself into something they are not? I miss my freedom --the freedom to be spontaneous and to just "get up and go!" ME robs. ME confines.

Loss of family, friends, community and health—each loss is devastating. Myalgic Encephalomyelitis has a life-altering power that few illnesses can create. But if we listen to the voices of those who are affected by ME, we will see people who struggle to move past ME cost and reach, everyday. Struggle to live, to





love, and to choose. The price of ME can be heard in these voices, voices that say Myalgic Encephalomyelitis is truly a “disease like no other”.

Change and keep the name of Myalgic Encephalomyelitis. Understand that this is a disease and not just a disorder as cited in the World Health Organization clause 93.3.

*Imagine that you have the worst flu you have ever had but you need to shovel 5 feet of snow off the roof of your house before it caves in from the weight, falling 30 feet to the ground and getting up to finish the shoveling. That's what it feels like to every sufferer who can still get out of bed every morning.*

The only people who are ready to care for us is us. We don't have that knight in shining armour - we have us, housekeepers, bricklayers, nurses, students, waitresses, athletes, cooks, chefs, hairdressers, teachers, doctors, truck drivers, professors, rocket scientists, artist, engineers, musicians, etc.... we must work together to make a change for all of us.