Public Comment
Charlotte Bowen

My name is Charlotte. I have been sick for 13 of 26 years. I am not the only one in my family as my father is also sick and has been for 27 of 52 years. His name is Bret. It's something of a perverse anniversary of being sick when at this moment, for the both of us, half of our lives have been taken from us by this evil, vicious, glutenous, overbearing, torturous, relentless, unforgiving, graceless, demanding, sadistic, behemoth of a chimera disease.

Who has and who has not understood about ME/CFS? Do you know why they did not understand (If it is because of misinformation, do you know where the got the information?)
About 95% of the people I talk to, including many doctors, don't care/don't believe I'm sick. I've frequently been told that it's all in my head, that I'm a hypochondriac looking for attention. I have no immediate visual indication that something is greatly amiss since the feelings and sight of exhaustion, pain and lethargy are common in a lot of other illnesses and therefore don't raise an immediate, identifying alarm. Those who do believe and do understand are those who are fighting a chronic illness themselves or those who know someone who is and can relate on a deeper level, who have seen in the long term the devastation that these relentless symptoms wreak each second on not just our health but, our sense of well being. The majority of those who hear of CFS misinterpret it as just being tired all the time due to its poorly chosen name and what little is commonly known out in the public, especially since not every person is going to pick up one of the few books that focuses on CFS to become more learned.

The speed of society moves so fast that anyone considered chronically sick and disabled to any degree are considered nuisances. Families who don't understand or don't want to take care of someone who is sick throw them in nursing homes where the care is just as poor or worse because the nurses and tenants don't care either. Often PWC are stuck in psychiatric wards because this disease is considered all in the mind where again, the care can be just as poor or worse. The same for those who find themselves in hospitals. There are just too many people who don't care, who don't want to care, who find that anything that slows them down from their own aspirations a severe disruption in the flow of their life and they will do anything that will rid them of the problem.

What have you had to change because of ME/CFS? What challenges with school, work, family, friends have you faced because of ME/CFS?
I can't move out of my parents' house. I had to drop out of college for five years. And though I've been able to go back, I can only endure one or two classes and I have to fight and struggle through brain fog, pain, lethargy, listlessness, malaise, etc. to meet deadlines and such, often making myself sicker. This fight is made worse by the physical activity of being on campus, trekking between classes and the energy necessary to get to and from the campus. While online courses are more friendly in the physical aspect, they still possess the same hurdling challenges. I have no dating life; barely a social life. My friends are very few, most of my relatives are annoyed, distant and disinterested. I can't work for long periods of time and there is no true way to truly predict exactly when and how long I will be able to do something consistently before I must quit or how one thing, regardless of size and significance, will tip the scales and what the

repercussions will be. If energy were money, my allowance/paycheck would be a handful of nickles and dimes that I must budget each day with the constant awareness that without notice, something big and expensive will come along that I cannot avoid and must pay for it regardless if I'm in the black or in the red. For others, this allowance can be mere pennies or more generous.

How has ME/CFS impacted your life?
It sucks to be sick. It really sucks. I reflect back on what I was once capable of doing, what once came so easily, and I sob at how badly I've been robbed. Most of the physically demanding activities that I love I can't do anymore; their lesser cousins and even lesser cousins than those I can just barely do. Simple math is a major challenge. I once was very proficient with words, having an extensive vocabulary that gave my writing an exciting life; now I find myself looking up words because I don't know their meaning, much like an elementary student; even my ability to spell even the simplest of words without spell check has deteriorated severely. I've had to downgrade my expectations for my life; the dreams and aspirations from the yesterdays when I was healthy are now a galaxy beyond my reach in the times of today. As for the tomorrows, I must constantly keep myself in check, to keep myself from dreaming too big and then falling flat on my face because I couldn't reach the expectations and goals that I had set. I've had to learn when shit hits the fan and I'm experiencing a bad day that I have to put everything on “pause” like some game until my “battery” recharges and then pick up where I left off, always aware of the low charge and that sooner or later, or even without notice, I must pause the game once again and let the bad battery charge up as much as it can. When I see those around me who are far more able-bodied than me, I feel so envious and depressed I could easily vomit. When I see those who are worse off than me, who are bed ridden and in wheelchairs, I cry and feel guilty because I'm able to move about the house and even go outside. When I watch those who are near my age run off to many social activities and leave me behind, who live such lively and exciting lives, who have college degrees, who have families, who have careers, I feel so lonely and ostracized. Because my face isn't commonly seen, I'm easily looked over and forgotten. So often I feel so hopeless.

Since becoming ill other maladies have followed; some have recognizable names like restless leg syndrome, multiple chemical sensitivity, bipolar depression, and low blood pressure. Others likely don’t because no doctor nor specialist that I have seen can tell me what it is that is making me sick. I can't maintain my body temperature. I'm frequently dehydrated because my body doesn't effectively absorbed the water that I drink. Too frequent are times when no matter how hard and how deep I breathe I can't get enough oxygen and it's not because of asthma or another lung infection. Too often I will climb a small flight of stairs and feel like I've just run a marathon. I've become victim to vicious recurrent infections of which the 'cure' is nearly as bad as the infection considering the heavy regime of antibiotics that I must take to overcome them. With no seen cause I can run a slight fever; have a raspy and sore throat like I have strep; my lymph nodes will be swollen and tender sometimes to the point that even loose-fitting clothes cause significant discomfort. Something I've eaten or drank has the potential to wreck having from the inside, sending sharp pains that cause me to buckle over or curl up while praying for their quick end. And that something is likely food or drink that I've ingested in the past and had no problem with it before.

My sleepless nights are filled with pain that refuses to let me slumber. The persistent, unrelenting

phenomenon that comes with restless leg syndrome pulls at my legs, squeezing them until the major muscles are tight beyond the levels that I can reach at my own discretion and then tighten even more until each leg can no longer withstand it and writhe so drastically that I cry. When the pain is so severe I beat my own legs to be rid of that feeling, to release the muscle fibers from the torturous prison. Like a prisoner of war they are not freed without consequence. Shortly after their liberation, each spot that I struck with my fist gives rise to a bruise that will not fade for many weeks. The freedom is short lived as the next time the yearning for sleep comes, my legs are ensnared and taken as prisoners once more. Like a battalion coming from some other direction, pain from headaches of all levels, be them severe and/or minor, from bone deep heavy pulsing waves, from inflammation that encompasses all with no known precursor, stretch thinner any remaining defenses that I have, abandoning me wherever I may lay, begging from some reservoir in my conscious mind for it all to end.

For most people, minor injuries like whacking a limb on something and consequently feeling pain, that pain quickly transitions from the sharpest zones to the dullest zones or the point where it doesn't hurt any longer in a manner of seconds or minutes, whatever have you. For me, recovery takes much longer. And the more intensive the injury, the longer it takes. This is so much so that I find myself imagining how long it would take for me to recover from whichever injury that someone I happen to be watching sustains and feel miserable that I have become so weak.

The senses that guide people through the world are not excluded from this war within. Already excessively responsive to any stimuli, adding multiple chemical sensitivity is adding fuel to the raging, out of control, wildfire. Brilliant lights shoot sharp knives of pain into my head, traveling through the nerves that connect my eyes to my brain, exploding within each lobe as it blinds me, much like a migraine attack. The slightest of smells can instigate nausea and more migraine-like headaches. Smells as potent as laundry detergent, dish liquid, perfumes and colognes, someone who has just smoked, to as insignificant as someone's body odor and the narrow hint of the smell of tobacco, an animal cage, a baby's soiled diaper, the smell of a flower, the smell of fruit, the smells of cooking, the after smells of someone who has just showered, all have the potential to steal away my energy without regard or remorse. The taste of something can become extremely painful. Something sweet, sour or bitter, even in the slightest hint, can cause my mouth and throat to protest with sharp agony, the glands beneath my tongue seizing up and burning and continuing to burn until I am able to even more painfully massage them until they relax. I am super sensitive to sounds, only able to withstand the quiet and reserved volumes. The sound of someone talking can be enough to overwhelm. Public places with many people and many sounds cause me to succumb to exhaustion in minutes or less and then metamorphose into physical pain. Just the sight of seeing so many people is often overwhelming. The shriek of a child throwing a tantrum and/or their receptive guardian shouting at them in turn are the worst that I have encountered.

How does PAIN impact your life?

I'm lucky I suppose. After several years I have my pain mostly contained or at least, I know what to steer clear from to keep the major pains away. I don't have to rely on narcotics and other strong medications to combat it like other persons with CFS that I know who are in chronic pain and narcotics only take the edge off of it. However, sometimes it just flares up and if it's really

bad, any sort of movement hurts and contact with surfaces hurts. I want to lie down and rest, to wait for the pain to go away. But lying down on a couch or my bed hurts just as much. When the pain gets really bad and I have to move to use the bathroom, I fear that my legs will collapse underneath me, never knowing which step will be the one that buckles and sends me crashing to the ground. I have had to sit on a stool in the shower for the same reason. Public places, especially those with high volumes of noise, crying, shouting, tantrum throwing kids and their parent, packed with people (and even just lightly populated) cause pain on so many levels and in so many areas because there is just too much and it's too overwhelming to process. And because I have experienced these various levels of pain, I'm much more leery and afraid to be active in any sort of way for fear of having to endure the long periods of agony that are sure to follow; a direct opposite of the me that was 14 years ago, the me that would push herself to just passed her limits and become stronger for it, not progressively weaker.

WHILE challenges occur in everyone's life, the challenges people with ME/CFS face, tend to tip them over the edge of their envelope.... HOW can these challenges be minimized to help patients use their scarce energy resources effectively and not just in fighting challenges?

To get around I either have to use public transit or rely on friends and family. Friends aren't always available and public transit is horrible on so many levels, having high demands on physical and mental energy, especially when the vehicles are packed and/or turbulent and/or contain children. While there is a flexible transit program, to use it is expensive and it's not too considerate to PWC and others who suffer in similar ways. Plus it has since reduced the number of miles that it will go off route to answer a request for a pickup. And so I still have to walk however many blocks to the closest stop to board. Taxi service is way more expensive and quite often just as inconsiderate. Maybe more PCP offices that don't also treat pediatrics. Doctors' offices that have a separate room for those who are highly sensitive to sound, not just for PWC. Offices that aren't cleaned with strong chemicals that leave odors even after several hours, especially those with perfumes which would also benefit asthmatics. An inexpensive grocery or fixed meal delivery service for those who are house bound and don't have the ability to leave their homes without the aid of another. An inexpensive taxi service program with drivers familiar with persons with chronic illnesses who must rely on other people to get where they need to go. These ideas don't need to be considered strictly for PWC, they can expand to include other such situations.

WHAT should be done to ensure that people DO understand about ME/CFS? WHAT do you think can readily be changed about that and how do we move forward towards that change?

More needs to be put forth in understanding this bitch of a disease. More needs to be put into increasing public awareness. I believe that the more people are aware of, especially doctors, specialists and care givers, more will be put into research and sequentially, better treatments and diagnoses. And I believe that it will be more accepted overall. It isn't seen as readily as cancer. It isn't seen as readily as autism. It isn't seen as readily as diabetes. It's not being advertised to make the public aware like Fibromyalgia and shingles. Even though it's becoming increasingly more prevalent, there aren't enough people out there who accept its existence and therefore so many people suffer unnecessarily. People also need to understand that CFS is a dynamic disease that is evolving faster than research can keep up. While symptoms can fade and disappear, they can also

fester or become something new. What remedies and therapies that work today to help alleviate those symptoms are not guaranteed to work as effectively or at all tomorrow, or the day after, or the week after that.

Those of us who are able to go out in society, even in the slightest degree, are too quickly misunderstood and believed to be liars looking for handouts. And YouTube isn't enough publicity. With the increase in accurate knowledge made available to the public, I believe that the medical costs of treatments will decline as diagnoses will come sooner, therapies will begin sooner and the quality of life will be increased and maintained. When I was diagnosed, the small amount of knowledge that had been obtained since the time my father was diagnosed has given me a lighter 'sentence' if you will, than his, where is nearly bed bound and must rely on opiates to take the edge off of the severe pain he experiences.