

Public Comment
Laurel Bertrand

Dear CFS Advisory Committee Members,

Last November, I submitted a written testimony which provided a glimpse into the lives of several patients with severe ME/CFS. One of those patients was named Emily.

I regret to inform you that Emily has since passed away. She died on March 18, 2012 from complications of ME/CFS following a prolonged hospital stay. She was 30 years old.

Emily was so young (just 6 years old) when she fell ill, and so young when she died. She had such potential; such vitality and desire for life. She should not have suffered as she did. She should not have died before she ever had the chance to fully live.

With her family's permission, I am including Emily's own appeal below, written in the year prior to her death. Please read it carefully.

As Emily herself states, severe ME/CFS is not rare. Yet, as a group, we are largely ignored -- by the government, researchers, medical community and even by many ME/CFS specialists and organizations. This is in part because no one sees us. We are completely confined to our homes and our beds, and thus made invisible. You cannot be aware of what you do not see.

However, it is through testimonies like Emily's that you can now be made aware. It is my hope that Emily's story will open your eyes and inspire action. It is my hope that she will help you to understand just how devastating this illness truly is, how dreadfully sick we are and how desperately we need help.

Thank you.

Sincerely,

Laurel Bertrand

Attachment: Emily's Appeal

Emily's Appeal

(Permission to re-post)

My name is Emily. I developed the neurological condition Myalgic Encephalomyelitis (ME) when I was 6 years old. In April 2011 I turned 30. I still have ME.

ME coloured every aspect of my childhood; it painfully restricted my teens and it completely destroyed my twenties. Now, as I move into the next decade of my life, I am more crippled than ever by this horrific disease.

My doctors tell me that I have been pushed to the greatest extremes of suffering that illness can ever push a person. I have come very close to dying on more than one occasion. If you met me you may well think I was about to die now - it's like that every single day. After all these years I still struggle to understand how it's possible to feel so ill so relentlessly.

My reaction to small exertions and sensory stimulation is extreme. Voices wafting up from downstairs, a brief doctor's visit, a little light, all can leave me with surging pain, on the verge of vomiting, struggling with each breath and feeling I'll go mad with the suffering. Of course it can also be as bad as this for no particular reason - and often is. I cannot be washed, cannot raise my head, cannot have company, cannot be lifted from bed, cannot look out of the window, cannot be touched, cannot watch television or listen to music - the list is long. ME has made my body an agonising prison.

My days and nights are filled with restless sleep interspersed with injections, needle changes (for a syringe driver), nappy [diaper] changes (as well as experiencing transient paralysis and at times being blind and mute, I am doubly incontinent) and medicines/fluid being pumped into my stomach through a tube. My life could be better if I had a Hickman line (line which goes into a major vein and sits in the heart) for IV drugs and fluids, but such a thing would likely kill me. I'm on a huge cocktail of strong medications which help, yet still most days the suffering is incomprehensible. During the worst hours I may go without the extra morphine I need as I feel so ill that the thought of my mother coming near to administer it is intolerable - this despite pain levels so high that I hallucinate.

I live in constant fear of a crisis driving me into hospital; our hospitals have shown such lack of consideration for the special needs of patients like me that time spent in hospital is torture (eased only by the incredible kindness shown by some nurses and doctors) and invariably causes further deterioration.

Many days I feel utter despair.

But, unlike some sufferers, over the long years in which I've had severe ME (the illness began mildly and has taken a progressive course) I have at least had periods of respite from the absolute worst of it. During those periods I was still very ill, but it was possible to enjoy something of life. So in these dark days I know there is a real chance of better times ahead and that keeps me going.

My entire future, and the greatly improved health I so long for, however, currently hinges on luck alone. This is wrong. As I lie here, wishing and hoping and simply trying to survive, I (and the thousands like me - severe ME is not rare) should at least have the comfort of knowing that there are many, many well-funded scientists and doctors who are pulling out all the stops in the quest to find a treatment which may restore my health and that the NHS is doing all possible to care for me as I need to be cared for - but I don't. This wretched, ugly disease is made all the more so through the scandalous lack of research into its most severe form and the lack of necessary, appropriate support for those suffering from it. This is something that must change.

And that is why I tell my story; why I fight my painfully debilitated body to type this out on a smartphone one difficult sentence at a time and to make my appeal to governments, funders, medical experts and others:

Please put an end to the abandonment of people with severe ME and give us all real reason to hope.”

By Emily Collingridge, 1981-2012

©2010-2011

Author of Severe ME/CFS: A Guide to Living (See www.severeME.info.)