



#SEVEREMEDAY: THE TRAGIC STORIES OF SEVERE ME/CFS

Each year on August 8, Severe ME/CFS Awareness Day, we reflect on the tremendous toll myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) takes on individuals suffering from severe symptoms, and those members of our community who have been tragically lost. We take time to remember, recognize and regret the harm caused by this disease.

Body Count: The Tragic Stories of Severe ME/CFS

“...the opposite of life is not death, it's indifference” – Elie Wiesel

They're known as the 'invisible' ones, the severe ME/CFS patients that governments, doctors, researchers and communities refuse to acknowledge. August 8 has been set aside to remember the suffering of these invisible severe ME/CFS patients.

People living with severe ME/CFS – 25% of those diagnosed – are often bed-bound and experience great difficulty with everyday tasks. Severe M.E. robs people of independence, and many require assistance with eating, showering, and even standing. Their symptoms can worsen from light, sound, and movement. Some need 24-hour care. Severely affected are particularly vulnerable from lack of medical attention, understanding, and home attention.

Here's how UK-based [The 25% ME Group](#) describes serious ME: “Those with severe Myalgic Encephalomyelitis are either bedbound and/or virtually or completely housebound ... They are often too ill to use a wheelchair, or can only do so to a very limited degree. Many need to spend their time lying flat in silence and darkness to avoid deterioration. Some are tube-fed, incontinent, unable to communicate, allergic to medications, and unable to move.”

Those with very severe ME/CFS experience profound levels of suffering and extreme symptoms, which can be life-threatening. Life may be reduced to basic survival, struggling moment by moment to breathe, eat, and drink, while enduring extreme pain.



Solve M.E.

“As well as severe disability, most have experienced financial hardship and relationship difficulties as a result of being seriously ill with a frequently misunderstood disease.”

The 25% ME Group is uniquely placed to talk about the nature of the illness. It is a charitable organization managed entirely by volunteers (most of whom are severely affected by ME/CFS) and was set up to offer support services to those severely affected by ME/CFS, and those who care for them.

What is ME/CFS?

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a chronic, complex, neuroimmune disease that profoundly limits the health and productivity of patients and is often triggered by an infection. There is no cure for ME/CFS, nor are there any FDA-approved drugs or treatments. The main symptoms are extreme exhaustion (exacerbated by activity), cognitive dysfunction and unrefreshing sleep. Other symptoms may vary.

Remembering Sophia Mirza

August 8 is the birthdate of Sophia Mirza, hence the reason for it being chosen as Severe ME Day.

Sophia was bed-bound with severe ME/CFS and was a victim of medical abuse. Her doctors refused to believe that ME was a physical disease and so she was forcibly taken from her bed by social workers, police officers and doctors, and kept in a psychiatric facility where she received inappropriate treatment and care.

Accounts of Sophia's treatment, by Criona Wilson (Sophia's mother) are chilling.

“In July, the professionals returned – as promised by the psychiatrist. The police “smashed the door down” and Sophia was taken to a locked room within a locked ward of the local mental hospital. Despite the fact that she was bed-bound, she reported that she did not receive even basic nursing care, and her temperature, pulse and blood pressure (which had been 80/60), were never taken.

Sophia told me that her bed was never made, that she was never washed, her pressure areas were never attended to and her room and bathroom were not cleaned. The nurse



Solve M.E.

asked me to cook for Sophia as the processed hospital food made Sophia more ill. Sophia also had to deal with all the nurses constantly going into her room and talking to her.”

Sophia subsequently died of ME/CFS at the age of 32. Her post-mortem revealed widespread inflammation in the spinal cord (ganglionitis).

You can read more of Sophia’s story [here](#).

Remembering Emily Collingridge

On March 18, 2012, Emily Collingridge died of a respiratory arrest after a long battle with severe ME/CFS.

In this so-called ‘age of modern medicine’ her story is both tragic and confounding, a quite unbelievable narrative of institutional incompetence, disregard and abuse.

In Emily’s own words: “I found myself spiraling into a level of illness that was both shocking and overpowering in its severity. I had no idea that modern medicine could allow such suffering. I lost the ability to speak, to see, to move. I was doubly incontinent, often paralysed, tube fed and in unbelievable pain, only partially relieved by high dose morphine.

“My nausea was so extreme that it had to be treated with drugs normally reserved for patients undergoing chemotherapy. I could bear no stimulation, even though I couldn’t open my eyes and was in a blacked out bedroom, my eyes had to be covered at all times; I wore earplugs for 23 hours per day and someone’s mere presence in my room was like an assault. At times I didn’t recognise my own mother and was confused where I was.”

“The consultant put in charge of her care was unsympathetic, dogmatic and overbearing. He confessed to a limited knowledge of ME/CFS and yet, when she expressed her lack of faith in him, he replied that he was all that she had. During her eleven week stay she had to tolerate endless failed attempts to take blood from her tiny veins, painful injections and regular changes of sites for minimal sub cut fluids while she vomited several times a day.”



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Emily was an inspirational ME/CFS advocate. Her own struggles gave her an insight into how desperately those with the illness in its most severe form needed practical, understanding advice. During a period of remission she researched and wrote [ME, Severe ME/CFS: A Guide to Living](#) (2010).

A final plea in Emily's own words: "Please put an end to the abandonment of people with severe ME/CFS and give us all real reason to hope".

Emily may have lost her personal battle, but her battle on behalf of all those still suffering from severe ME/CFS should not be ignored.

Remembering Alison Hunter

Another victim of the system is Alison Hunter. Alison died in 1996, aged 19, from complications arising from ME/CFS which included seizures, paralysis, gastrointestinal paresis and overwhelming infection resembling Behcets Disease. Such complications are rare and only present in a severe subgroup.

Alison courageously fought ME/CFS for ten years and was an unstinting advocate for young people. She was the founding president of ME Young Adults (MEYA), established in 1992 at Royal North Shore Hospital, Sydney.

Again, despite her considerable physical distress, Alison suffered at the hands of indifferent and incompetent medical practitioners. Medical writer for the Sydney Morning Herald, Julie Robotham quoted James Isbister, the head of haematology at Royal North Shore Hospital, who treated Alison when she was a child and again when her illness returned in her teens.

"To be honest I felt helpless towards the end," Isbister says. "On many occasions I was extremely embarrassed about the way she was treated by the system. A lot of the terrible things Alison went through were doctors projecting their own fears and inadequacies. How anyone could not think she had a major medical illness was beyond me."

Alison, he said, was, "like someone going through a concentration camp" – suffering terrible physical distress compounded by insults and inhumanity.



Solve M.E.

Remembering Theda Myint

The lack of services for severe ME/CFS patients was underscored in the case of Perth (Australia) ME/CFS sufferer Theda Myint whose health deteriorated to the point where she considered suicide but repeated pleas for an in-home pain relief treatment **were knocked back** by the hospital treating her.

After a ten-year battle with the illness, on July 25 2013, just one day after her last medical appointment in which a neurologist advised her that she had tried all options available for pain management, Theda “euthanased” herself.

You can read more about Theda Myint [here](#).

Remembering the countless others

Sophia Mirza, Emily Collingridge and Alison Hunter are not isolated cases of institutionalized medical abuse towards ME/CFS patients. Thousands have died either directly due to the illness or from suicide as a result of suffering caused by the illness. Most had suffered some form of mistreatment, whether through medical incompetence, government indifference or social neglect.

The National CFIDS Foundation maintains an [In Memoriam](#) list of those who have died from ME/CFS. It includes a dedication to William Young, “who began the list and who compiled a great number of names on this list.”

The majority of these patients did not have the medical care they needed; they suffered unremitting pain with little hope of relief or comfort. We acknowledge their suffering and hope that they have not died in vain.