

## Testimony

Shiloh Moore

To Whom It May Concern at the CFSAC:

Thank you for the opportunity for us to share with you our testimonies of our experiences with Chronic Fatigue Syndrome.

I am now 30 years old and have had CFS and Fibromyalgia since I was 10. I had strange pains, moving all throughout my body through primary school. We went to doctors who told me I had 'growing pains' which was normal and it would go away. Nobody else complained about their growing pains so I tried to not complain. By age 12 I was in constant pain but still was told it was my fault for having bad posture and leaning when I stood. 18 years later I have not had a pain-free moment.

Aged 13 and 14 I was still undiagnosed. My father and brother were diagnosed with CFS and we joked 'it was the women of the family that were strong'. My pain was increasing and was constant but I was still told it was normal and I believed the doctors as they were authorities. I was a straight A student and played flute and hockey. I was sensitive to light (this gave me a headache) so I wore my sunglasses as I played hockey and I would play half a match and then go home with a splitting headache that I called a 'hockey headache'. I would sleep for hours afterward. Holding the flute was painful too, but I thought this was normal.

Finally at the end of the year I was 14 I went to a doctor who checked the Fibromyalgia trigger points and found that all 18 points hurt on me. The doctor pressed them on Mum and only 2 hurt – where she'd had an injury. He asked to speak to my parents alone and then told them I had Fibromyalgia. He thought I was too young to be told face to face.

The diagnosis gave me relief that there were others in the world with similar pains and tiredness and a huge multitude of various symptoms that I also struggled with. I was not alone. I was not making this up. My pain was NOT 'normal' and I needn't fear getting in trouble for complaining about pain that everybody had but nobody talked about.

The next year my health plummeted. I could no longer hold up nor even purse my lips into the shape to blow to make music on my beloved flute. I stopped playing hockey and dropped all extracurricular activities. Then I attended school less and less and studied from home. I still topped the class in many subjects. By the end of the year I was 15 I could no longer attend school at all and could not study at home either.

My cognitive functions were so affected that 3 months after achieving 98% on my Advanced Maths exam, I turned 16 and could not think without a headache to work out how many candles it would need to make two rows on my cake. I could not pour juice from the jug into a glass without spilling it as the concentration needed to pour it neatly gave me a splitting headache.

The year I turned 16 my health deteriorated to being completely bedridden for 12 months. I could not sit up. I could not lift food to my mouth. When fed by my parents it hurt to even chew. I could not bathe myself. Every second day my mum would carry me to the shower, sit me slumped on a stool and hose shower me. Then she would dry me and carry me back to

bed. I would need hours of sleep to recover from the exhaustion and pain from the effort. I was not flexible enough to fit in a bath and if I was in it, I could not get out easily, so we used the stool in the shower instead.

I suffered from terrifying night terrors. I woke the household with my screaming. I also clenched my teeth, dug my fingernails into my hands and kicked my feet.

The anxiety followed me through to the daytime.

I was not depressed from clinical depression, but at every stage I grieved every loss. The loss of who I formerly identified as being. Loss of all my passions, my flute, my hair which I had to have cut off as it was too heavy, no longer being with my friends at school, loss of being able to study and learn which I loved and achieved highly at.

When bedridden I could barely communicate. I could not write and most often could barely talk. Mum and Dad gave me a buzzer to use to call them and I would raise my thumb for 'yes' and lower it for 'no'. Often the movement of my thumb was painful and exhausting. I felt trapped in my head and longed to be able to express myself.

I was sensitive to light, sounds and smells. We darkened my room, and the tv at the other end of my house would be turned low and even this noise could drain me of energy. Smells of food cooking in the kitchen, also at the other end of the house, would drain my energy and I had to force myself to eat. I lost a lot of weight.

After a year, I gradually improved. On a good day I was able to sit up for half an hour so we bought a wheelchair so Mum could push me around out of the house.

I was interviewed for social security at this stage and was sent to their psychiatrist. He said he thought it was appalling that I was using a wheelchair as it is not healthy for a teenager's mindset to be seen as disabled. He had no clue. The wheelchair to me symbolised freedom and escaping the walls of home. All he could see was me in the half hour I was sitting up, looking healthy but in a wheelchair.

In the 14 years since being bedridden, my health has been improved from that state, but is still far from healthy and is not stable. I can now walk short distances unaided – but never free of pain. I am still in constant pain, but now if I lie down all day I feel worse, so I need to vary positions. It hurts to lie down, it hurts to sit up, it hurts to stand, it hurts to walk. But I have to move through those positions to have the most alleviation of pain.

I go to hydrotherapy twice weekly (to gently stretch muscles and relax in the water), physiotherapy weekly, podiatry, colonic irrigations for gut problems, GP for fortnightly injections and scripts and monitoring, and I'm extremely fortunate to have care from a specialist in the field of CFS. I have seen him regularly since diagnosis. He has a long waiting list and is hard to get in to as there are not many specialists around in this field. I am very fortunate to have had his care. Having said this, even having been on the latest treatments I am far from cured. I hate to think what state I would be in if I had not had access to these treatments. I respect that he is honest and when he doesn't know how to help he admits it.

I take 20 tablets of a morning and 10 at night. I sort them into bottles to make up a fortnight's worth. It takes over an hour to do this, and that is the only activity I am up to doing that day.

I would try more treatments than this, but my medical expenses already cost far more than my rent and other living expenses. I struggle to afford all the above mentioned treatments as is.

On a good day I can sit up for a maximum of 4 hours and the rest of the day is spent resting. I sleep on average 14 hours a day. This is me at my healthiest in 15 years!!!

Thank you for the opportunity to share my story. I am one of the lucky ones in that I have had support from my family and doctors. Since diagnosis I have been believed. Many people aren't so fortunate.

There are many things we CFS/FM strugglers would love to see to help us. Some of these I'd personally like to ask from you are these:

- For people with CFS to be supported by the government with Social Security and Medicare, financial aid and carer support.
- Education for all GP's and Physicians from people with experience and knowledge of the field.
- CFSAC and the government to work with experienced CFS doctors to learn about the condition from those who truly know.
- That money be put into research
- May there be long term CFS Studies (the longest study done has been for 5 years. Many severe patients have CFS for longer. I've already had it 20 years and I am only 30 years old.)

Thanking you gratefully for your time and for listening.

Yours Sincerely,  
Shiloh Moore