

Journal Through Fibromyalgia

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L'auteure nous décrit son expérience d'une vie vécue avec la fibromyalgie

Fibromyalgia (FM) is an increasingly recognized chronic pain illness which is characterized by widespread musculoskeletal aches, pain and stiffness, soft tissue tenderness, general fatigue, and sleep disturbances. The two most common and devastating symptoms are pain and sleep disorders. It is estimated that three to six per cent of the population are afflicted with FM and 80–90 per cent of these are women (Arthritis Society). The situation is slowly improving. In the past it would often take years for a diagnosis and women were frequently thought to be imagining it. I was one of the lucky ones because I had an outstanding family doctor who pushed specialists until they discovered what was wrong with me. The following excerpts are from my 1982 journal covering the eight months from onset to diagnosis.

January 4

Slept very badly.

January 10

Seem to be in a fair bit of pain today.

January 11

Still in pain.

January 12

Bad night last night.

January 13

I am really upset about not being able to sleep. I just feel it has something to do with my physical condition. I hope it sorts itself out soon because I am very fatigued.

January 15

I phoned Sam [family doctor]. He finally persuaded me to

try the sleeping pills for five nights. I'm so exhausted I gave in on the issue.

January 19

Sam is doing some more tests but I doubt they will show much.

March 12

I am very tired and very irritable and in pain.

March 13

I know now I will have to quit the job. I am too out of it physically.

March 14

The sun is shining and I feel like murder. I obviously cannot continue this job as it is taking too much out of me physically. I continue to be in pain.

April 27

I still feel really weak. I hope they find out soon what is wrong with my body.

May 3

I got a lot of sleep for a change but I still feel so weak it is frightening.

May 4

I feel crazy seeing doctors so much and I really am beginning to lose hope of a simple solution being found.

May 7

The drug seems to help the pain somewhat and, as a consequence, there were times today when I only felt half-exhausted.

May 11

Had an appointment with the internist. I am becoming

increasingly upset about my health. Dr. R. is starting to doubt. I recognize the signs.

May 14

My legs really bothered me last night. It feels as though I have boiling, bubbling blood running through my whole body but especially my legs. When it is really bad, my arms ache too.

May 15

My legs are still bothering me.

May 17

God, how I hope this test turns out to be the answer because I can't live like this much longer. After going to the store I was so exhausted I fell asleep. I can't go on like this much longer as it is sending me into despair.

May 18

My appointment with Sam went well. He is so kind. I wish all doctors were as good as him.

May 19

Bad sleep last night. My legs ached.

May 25

A bad day. I felt zapped and my legs ached.

May 28

I did finally get hold of Dr. R. and I am seeing her on Monday. The problem has to be solved soon or I will go crazy.

May 31

Dr. R. did not go very well and I seem to get more and more upset about it. I really feel as though my life will never improve.

June 8

I am really depressed and I don't want to go on living like this. I hate what has happened to my body and my life as a result. I am too damn young [33 years old] to go on living like this forever.

June 14

My legs are bothering me. There is pain as well as weakness.

June 15

I am so tired and my legs are hurting me a lot. Phoned Sam. Spoke to him for a while. I think he is beginning to doubt me too.

June 17

I phoned Sam and had to wait hours for the return call. He is going to do some more blood tests tomorrow but I no

longer think they will find out quickly what it is that is wrong with my body.

June 22

My legs are really bad.

June 25

My legs are not hurting me as much and I don't seem as edgy. The other symptoms are still there.

June 27

I have so little energy; sometimes I think I really have gone crazy.

June 30

Talked to Sam and the tests were negative—of course. It will be almost two weeks before I see another doctor.

July 6

Sam has set up more appointments for me. My legs were killing me in the evening.

July 9

Still feeling strong emotionally but physically terrible. Sam was pleased to see me up, but sorry to see me hurting. He wants me to try an anti-inflammatory drug and my legs hurt so much I am going to try it, allergies be damned.

July 10

Still feel good emotionally and mentally but not physically. I did get a bit nauseous and know it is the drug.

July 14

I tried to do some work on writing my book but I am so damn exhausted it is really impossible. I find it so frustrating.

July 16

I had a lot of pain in my legs in the evening.

July 19

My legs were really bad today which made me feel old and unattractive.

July 20

Did some work on my book today. It would be so much better if I was not so exhausted all the time. Also turns out I have a urinary tract infection.

July 22

Today was a bad night (sic). I woke up in a lousy mood and in pain after a fitful night.

July 23

My legs still hurt from yesterday but at least I don't feel like killing the whole world. I always feel old and ugly when

my legs bother me. Of course, I feel that way even when my legs don't bother me!!!

July 29

Dr. B. was really nice. I have many allergies and I am going to have to take appropriate action. Dust, pollen, cats, dogs, mould—the list goes on and on.

August 5

Went out early for the papers and found another ad for a job. I was not looking forward to Dr. L. He was very efficient and knows his work but even after he found a number of things wrong he still kept referring to depression and strain. I bet if this was his life, he wouldn't be so "up" either. Sam had warned me about him but it still pissed me off.

August 9

Typed a résumé and went through the papers. I went swimming in the evening. I expected to sleep well after it but no such luck.

August 17

The test was easy but I had to sit around the hospital for two hours. I started to walk down for my swim but my legs hurt so much I turned around and came home.

August 18

I had very bad cramping in my legs last night. It woke me up. They hurt all day.

August 19

I had my EMG this morning [EMG is a test involving the insertion of needle electrodes into muscles in order to record their activity]. The first part was bearable but the second half was very painful. I only hope it was worth it and the tests give some answers.

August 24

More upset and depressed daily. Up very early and out to get the papers. Found a couple of ads. I only stayed at the job I took yesterday [telemarketing] for two hours. I just cannot impose myself on people like that. My legs are *really* bothering me.

August 25

Went through the papers and then dashed off to a job I saw advertised. It went okay. After supper I went for a walk. When I got back, L. phoned and offered me the job. I decided to take it. It isn't nearly enough money but it will have to do for now and maybe I can survive on it while I finish writing this book.

August 26

I feel a bit insecure about my alarm clock and may have to buy another one! I got up at 6:25am. Left at 7:10 and got

there with a few minutes to spare. I am glad it is close enough to walk [20 minutes]. The job isn't too bad. In a lot of pain when I got home but I still went swimming in the evening.

August 27

Dr. L. said he looked closely at all the joints in my body and pointed out that my loose right shoulder is a result of what he said must have been a shoulder separation when I was very small! Interesting. He says my constitution is strong but I do have fibrositis [fibromyalgia]. As he said: "it won't kill you but it will hurt like hell." Wonderful!

I wish I could say my FM miraculously went away. When it is at its worst, I am up until 3.00 or 4.00 a.m. and I have to walk around my home until it calms down. My arms and legs jerk and the deep pain in my muscles actually defies description. Because FM sufferers rarely reach the stage four, restorative sleep, I wake up every morning exhausted, as though I have stayed up all night. I have had two periods of remission but have been in a severe phase for the past two years. Some people are lucky and have a mild case of it. According to the doctors, I am not lucky! The illness presents itself differently in each patient and doctors have not yet discovered the actual cause although a serotonin imbalance in the brain is the suspected culprit. There does seem to be a genetic pre-disposition to FM which is activated by a physical or emotional trauma to the body. Research on FM has moved ahead at a fast pace and it is important to keep up to date with this information. Medication and exercise are the two most effective ways of dealing with this illness.

Susan McNicoll lives in Vancouver and has been a writer for more than 30 years and has also run her own business for the past seven years. The book referenced in this journal will (finally) be published in 2005. She has also written four true crime books, including Ontario Murders and the just-released Jack the Ripper.

References

Arthritis Society, the. Available online: <http://www.arthritis.ca>. January 12, 2005.