

# **The Endometriosis Survivors Letter**

**Dear Parents, Partners, Friends, Families, Employers & Doctors:**

We have spent the last years of our lives apologizing for being stricken with a disease we did nothing to contract, and we can do it no longer. We are asking - again - for your understanding. We are not responsible for failing to live up to your expectations, the way you think we should. What you seem to fail to realize, is that you are just as much a part of the cycle of the disease as we are, because you are not getting the whole of our person and our capabilities.

We are not "lazy," we are not "whiners," we do not make the pain up "in our heads."

We have endometriosis.

We know that we look healthy on the outside, and that is sometimes harder to accept than if we exhibited the disease in our every day appearance. What you don't see is what our organs look like on the inside, and you don't see what living with it has done to our emotional well-being.

When we call in sick, it's not because we need a mental health day or to "go shopping." It's because we can't get out of bed from the pain. Do you think we like letting our careers suffer? Would it be easier for you to understand if we said we had cancer and looked the part?

When we get emotional and cry at the seemingly silliest things, or get angry for even less reason, it's not because we are "flaky women." It is because we are taking drug therapies to stall this incurable disease, or perhaps it's because we have come close to the breaking point after dealing day in and day out with the pain for which there is no defined cause or absolute cure.

When we can't have intimate relations with our partners, it is not because we don't love you or want to. It's because we can't. It hurts too much. And we aren't feeling real attractive right now.

When you, our parents, can't understand that since you are healthy, we should be too, but aren't - try harder. We don't understand it either. We need your support more than anyone's.

When we can't go to family gatherings or accept social invitations, it's not because we don't wish to share in your fun. It's because we feel like pariahs. You are all having such a nice time with your children and loved ones - we can't remember the last time we had a nice time, or the last time we were pain-free. We can't have a nice time with our children (some of us); because we were robbed of that chance before we were old enough to even care about having them in the first place. Do you think we need to be reminded of our battle with infertility by watching you and your babies? Or for those of us who were blessed enough to be able to conceive, do you think we want a constant reminder that we never feel well enough to spend

enough quality time with our children, or worse - that we might have passed this disease down through our genetics onto our daughters?

When you married us, you didn't know that we meant the "in sickness and in health" part literally, did you? We bet you were counting on at least a 50/50 split of that combination, rather than the 90/10 ratio you got. You are our caretakers, the ones who drive us to and from our doctors, countless surgeries, and emergency room visits. You are the ones who hear us crying in the night and see us break down during the day. You are the ones who wait on us hand and foot after surgery. You are the ones that go for months on end without sharing our beds with us. You are the ones that deal with our infertility right along with us. We strike out at you when we are hurting and angry, and you take it in stride. You are perhaps bigger victims of endometriosis than even we are. You are appreciated more than words can ever say.

Don't give up on us now.

As a medical professional, we are coming to you for help. We are asking you to do the job you were trained to do and ease our suffering. We do not need you to tell us that we are imagining the excruciating pain we live in, or worse yet, that it is "normal for a woman to hurt." Keep up with your research, find the cause of this disease and better yet, find a cure! Stop taking the easy way out and drugging us into oblivion so that we will quiet down. We want answers and it is your job to provide them. You were the ones that took the oath to heal - why do we have to try to do your job? Do you understand what it means when we tell you that we literally can no longer live a normal life and care for ourselves and our families? We're not drug seeking; we're answer seeking.

Are you not up to the challenge to find the answers?

To those we have called friends all our lives, why have you deserted us when we needed your compassion and understanding the most? Do you see the selfishness of your actions? When we can't get together with you, it's not because we don't like you or we don't care - it's because we are no longer capable of enjoying healthy leisure time. Our minds are consumed with our next doctor's appointments, what surgery we are going to have next, and why we feel so sick all the time. This is not about you - it never was and it never will be. It is about us. Please try to remember what the term "friend" means.

Try to walk one minute in our shoes. We have fought a war for the better part of our years. We are faced daily with physical pains we can't understand and mental anguish we can barely cope with some days. We face a society daily that doesn't even know the word "endometriosis," much less the ramifications of living with the disease. We have to face uneducated and unsympathetic doctors who tell us "it's all in your head", and "have a hysterectomy, it will cure you", or "get pregnant, it will cure you", when we know that it won't and have been dealing with infertility for the last however many years. Can't you see that?

We have to fight to get medical treatment that insurance companies don't deem necessary, or worse, we deplete our savings because aren't able to obtain proper care unless we pay for it ourselves and travel thousands of miles to the rare specialists that are few and far between. We have to have surgery after surgery and subject ourselves to horrific medications just to be able to get out of bed in the morning. This is not a conscious choice we made, it

was the hand we were dealt. It is enough of a war we wage just to try and live with some modicum of normalcy - don't make it harder on us by not seeing the reasons why.

Endometriosis is a disease that affects all of us.

Take the time to learn about it and understand. If you can do that, and you can join us in the battle for a cure, then we can one day return to our old selves and live a normal, pain-free life. We can have healthy relationships with our loved ones. We can stop taking the painkillers that numb our suffering to a degree and become part of the living again.

Please don't judge us and declare that we are all the things we are not - until you have lived with this disease ravaging your mind and body, you cannot speak on it.

Whatever doesn't kill us makes us stronger, someone once said. While endometriosis may not kill our physical body, it tries like hell to kill our spirit. It tries to kill every hope and dream we ever had of doing the things that make us happy. All of us are out here searching for a cure to put an end to the disease...and we are holding our heads high in spite of endometriosis and fighting it every single day.

We are asking you to take part in that battle and work with us beating it. Wouldn't it be nice to have back the daughter, wife, friend or loved one you once knew?

Think about it.

~The Sentiments of Millions of Endometriosis Survivors Around the World~

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