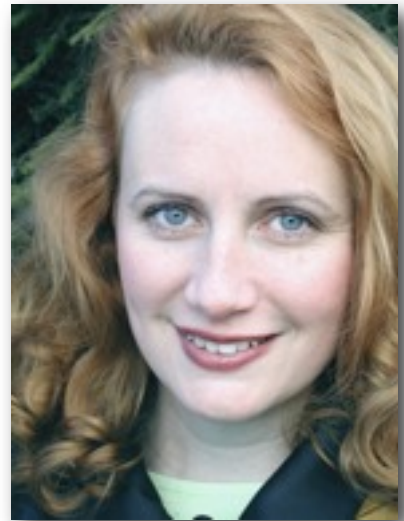


▶ **A Letter to My New Doctors** by Maureen McCarthy  
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I was a member of a women's group many years ago where our first couple of meetings included telling "the story" of our life in order to better understand where each woman was coming from. When I finished telling my story, a woman across from me said, "You know, after hearing that story, I would've thought you'd be the biggest bitch I'd ever met. But how remarkable that you're quite the opposite."

I was floored by her comment, not because she expected me to be a bitter soul, but because I hadn't perceived my life to be so terribly misfortunate. When the editor of this magazine, Julie Parker, invited me to write an article for this month's issue on Overcoming Adversity, the women's group experience came to mind. Julie doesn't happen to see my life as adverse either. She said to me, "This is not about poor Maureen, isn't she so brave. It's about understanding there is so much more joy to be had no matter what's going on." Well that got me thinking about how telling "the stories" of our lives help us provide others a window into how we see the world. And how can I better understand my own stories and filters that shape and create the life I live?

Last year I went to see a physician for the first time in 5 years. I have a rare, fatal lung disease that has filled my lungs with tumors and left about 10% oxygen capacity. I haven't been able to get insurance for years and have massive medical bills, so for me doctor/hospital visits were out of the question. In 2004 I finally made the decision to find a local internist and pulmonologist. It's a large practice, and I wasn't sure who I would be seeing or how much time I would be given. In preparation for my first appointment, I wrote the following letter to my new doctor:



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Hello!

*Since I am a new patient here, I thought I would take a moment to share some thoughts about myself and my history that I believe are important for my physician to be aware of from the beginning.*

*I've had Lymph.angio.leio.myo.matosis (LAM) at the very least since 1988 when I had my first pneumothorax (lung collapse), although it wasn't diagnosed until 1996 when a grapefruit-sized tumor on my left kidney ruptured and my kidney was removed. Since 1988 I've been on quite a roller coaster ride due to the fact that LAM is fatal (nearly all die within 10 years of onset), very few doctors are familiar with it, there's no known treatment or cure, and lung transplantation is not an option. This illness has totally affected my life, but not in the way you might think. I may have an illness, but I choose not to live a sick life. Our society has many stories around illness and death; how it feels, what it means, how difficult it is. I've found that I don't buy into those stories in the first place, so I don't have the experience of feeling sad or angry or overwhelmed.*

*I'm not someone who chases after "the cure," even though I no longer have a memory of a day without high levels of pain. I want to live my life to the fullest while I'm here, not as a victim of my health. I'm happy, at peace and I handle stress better than most anyone I've ever known. Dr. Tom Corbridge, my previous pulmonologist at Northwestern Hospital in Chicago, said he believes I'm still alive because I laugh so much. I would agree. You will find after knowing me that I am by far the luckiest person you will ever meet. The people and*

experiences in my life are so extraordinary they are beyond reason. I love my life, but I'm also completely OK with death, even if it's tomorrow.

I need you to know this because it's important for me to develop a partnership with my doctor that addresses my needs, but doesn't turn my life into an endless doctor's waiting room. Because I'm not expected to live much longer, I've recently been put on Medicaid, which I see as a privilege, not a right. I've spent so many years not able to obtain insurance that I currently have hundreds of thousands of dollars in medical bills. I don't take that lightly, and even though Medicaid is willing to pay my current bills, I intend to be as mindful as if it were my own money. I haven't seen a doctor on a regular basis in the last 5 years for lack of insurance, so I deeply appreciate the Medicaid.

That being said, what brings me to you is that everything associated with this disease has progressed a great deal in the past year or so. All the symptoms are either happening more often or are more pronounced. It brings my work to a standstill, which breaks my heart because you've never met anyone who loves the work she's done in the world more than me. It's been a transition and I may need some assistance figuring out how to manage these symptoms. Very rarely has any doctor looked at the whole picture of what this disease entails.



LAM is an estrogen driven disease, and even though the medical establishment has yet to understand the exact link, I can tell you without a shadow of a doubt after years of having this disease, that LAM is hormonally driven. I know this because the side effects are much more prominent around my period and INSANE when I'm pregnant. (I've had three children. My first son died before he was able to receive a heart transplant.) The amount of estrogen in my body translates into a host of side effects typically seen in pregnant women, only I have them constantly and to the nth degree even though I'm not pregnant. Some of these side effects are what tend to complicate my life on a daily basis and are what I may need help with: (Side effects were listed here.)

**\* One of the things that often complicates matters is that my body won't tolerate**

**ANY narcotics.** So even the eight pleurodesis surgeries (in essence a chemical burn of the lung tissue) I've undergone have been without

pain meds.

Because little is known about both LAM and how intensely hormones govern our bodies, I need a physician in my life who is willing to be open-minded and prepared to let me listen to my body to know what's right. It's important to have someone who's willing to question with me, and possibly do nothing when that's what I desire. It would mean a lot to me to have a doctor who will look at my whole experience of this disease rather than separate symptoms or occurrences.

Are you that physician?

Now I know that today's healthcare system leaves little time for doctors and patients to know one another well, but actually, I would rather see no one than to have a negative experience around my health. I think I do well because I do listen to my body, I'm not the least bit afraid to die, and I have more gratitude in my body than I can hold sometimes. My life is full of grace. I hope we can come together in a great partnership. Thank you so much for your time and the also for the work you do in the world.

with grace and love,

**Maureen**  
Maureen K. McCarthy

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At that first appointment I was fortunate to meet Dr. John Rogers who, after speaking with me and reading my letter, downheartedly told me he was leaving the practice in two weeks for a new job at an urgent care center. He said that after meeting me, he wanted to reconsider. "You're the kind of patient that made me want to go into medicine in the first

place." We had a wonderful, heartfelt conversation about our life's work and our great desire to be a force of good in the world. He then told me he would like to refer me to another doctor in the practice, Dr. Kim Morris, because he felt she would be a perfect fit for me. Boy was he right. Dr. Morris then read the letter, came in to meet me, and a year later she's one of my favorite people. Dr. Rogers also referred me to an excellent pulmonologist, Dr. Gail Clary, who again is the perfect person for me. She understands the way I live and think and is a great partner in making decisions. I adore her. Thank you John Rogers!

I wrote that letter because my experience of having this disease over the years, is that there are a lot of cultural, maybe even human expectations around having an illness and being told you'll die soon. We expect it to be hard, we expect to be sad, we expect people to fight death at all cost. And even though the medical community would disagree with me clinically, I know that I am the healthiest person you'll ever meet. The letter happened to be my way of letting my physicians know those weren't the beliefs I held, which in turn has made them care for me in a more personal manner.

I believe we are all a culmination of our stories. Everything we think and do is driven by the stories we experience and buy in to.

Our society has a lot of stories around illness and death in particular; how we should feel about it, how difficult it is, what it means to us and our families. I found many of these cultural stories caused me and others pain. More pain didn't really interest me. People say things like, "Knowing you'll have two young children left behind when you die must be horrible. It must be hard to get through the day with such high levels of physical pain. Losing your own child must be the worst experience imaginable." These words to me are nothing more than a story, and I have the ability to buy into them or not. I'm not saying those stories don't have their place, they do. I just thoroughly enjoy saying to myself, do I really want to believe them? Does it really serve me? Where's the law that says this should hurt? I'm not someone who sees a hurdle and is amazing at jumping over it. I actually don't see the hurdle at all, so for some reason I keep on walking and am rarely hindered. It seems bizarre, but it works for me.



I know I'm healthy. I don't need to do anything to be healthier, to me I live life fully, every day. What more could I ask for? I always found it funny that my doctors were so happy to see me when I came in for an appointment, until one of them told me it's because most days all they see are patients who are sick and irritable. Most people walk into the doctor's office focused on their pain and the doctor is the one to hear all about it. By the time many people get to the doctor they're frustrated about being sick, and because our cultural story says it's awful to be sick, their interactions might reflect that. A doctor's daily interactions are generally about the difficult, rather than the joyful. I'd never thought about it that way and it gave me a much greater appreciation for the work they do.

Adversity is defined as a state of misfortune or affliction. It's related to the word "adverse" which means negative or contrary, "a life of hardship", "a stroke of ill fortune". I know people might consider what life has dealt me as ill fortune, but I beg to differ. I know that I am the luckiest person you'll ever meet.

*Maureen McCarthy is a professional speaker, writer and facilitator who lives an outrageously great life in Flat Rock, NC, USA. She is co-creator of The Blueprint of WE Collaboration Document with Zelle Nelson ([www.blueprintofwe.com](http://www.blueprintofwe.com)) She wanted to find a huge field of sunflowers to lay in before she died, and the opportunity recently presented itself.*