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A Letter to Patients With Chronic Disease

Dear Patients:

You have it very hard, much harder than most people understand. Having sat for 16 years listening to the stories, seeing the tiredness in your eyes, hearing you try to describe the indescribable, I have come to understand that I too can't understand what your lives are like. How do you answer the question, "how do you feel?" when you've forgotten what "normal" feels like? How do you deal with all of the people who think you are exaggerating your pain, your emotions, your fatigue? How do you decide when to believe them or when to trust your own body? How do you cope with living a life that won't let you forget about your frailty, your limits, your mortality?

I can't imagine.

But I do bring something to the table that you may not know. I do have information that you can't really understand because of your unique perspective, your battered world. There is something that you need to understand that, while it won't undo your pain, make your fatigue go away, or lift your emotions, it will help you. It's information without which you bring yourself more pain than you need suffer; it's a truth that is a key to getting the

help you need much easier than you have in the past. It may not seem important, but trust me, it is.

You scare doctors.

No, I am not talking about the fear of disease, pain, or death. I am not talking about doctors being afraid of the limits of their knowledge. I am talking about your understanding of a fact that everyone else seems to miss, a fact that many doctors hide from: we are normal, fallible people who happen to doctor for a job. We are not special. In fact, many of us are very insecure, wanting to feel the affirmation of people who get better, hearing the praise of those we help. We want to cure disease, to save lives, to be the helping hand, the right person in the right place at the right time.

But chronic unsolvable disease stands square in our way. You don't get better, and it makes many of us frustrated, and it makes some of us mad at you. We don't want to face things we can't fix because it shows our limits. We want the miraculous, and you deny us that chance.

And since this is the perspective you have when you see doctors, your view of them is quite different. You see us getting frustrated. You see us when we feel like giving up. When we take care of you, we have to leave behind the illusion of control, of power over disease. We get angry, feel insecure, and want to move on to a patient who we can fix, save, or impress. You are the rock that proves how easily the ship can be sunk. So your view of doctors is quite different.

Then there is the fact that you also possess something that is usually our domain: knowledge. You know more about your disease than many of us do - most of us do. Your MS, rheumatoid arthritis, end-stage kidney disease, Cushing's disease, bipolar disorder, chronic pain disorder, brittle diabetes, or disabling psychiatric disorder - your defining pain - is something most of us don't regularly encounter. It's something most of us try to avoid. So you possess deep understanding of something that many doctors don't possess. Even doctors who specialize in your disorder don't share the kind of knowledge you can only get through living with a disease. It's like a parent's knowledge of their child versus that of a pediatrician. They may have breadth of knowledge, but you have depth of knowledge that no doctor can possess.

So when you approach a doctor - especially one you've never met before - you

come with a knowledge of your disease that they don't have, and a knowledge of the doctor's limitations that few other patients have. You see why you scare doctors? It's not your fault that you do, but ignoring this fact will limit the help you can only get from them. I know this because, just like you know your disease better than any doctor, I know what being a doctor feels like more than any patient could ever understand. You encounter doctors intermittently (more than you wish, perhaps); I live as a doctor continuously.

So let me be so bold as to give you advice on dealing with doctors. There are some things you can do to make things easier, and others that can sabotage any hope of a good relationship:

- 1 Don't come on too strong - yes, you have to advocate for yourself, but remember that doctors are used to being in control. All of the other patients come into the room with immediate respect, but your understanding has torn down the doctor-god illusion. That's a good thing in the long-run, but few doctors want to be greeted with that reality from the start. Your goal with any doctor is to build a partnership of trust that goes both ways, and coming on too strong at the start can hurt your chances of ever having that.

- 2 Show respect - I say this one carefully, because there are certainly some doctors who don't treat patients with respect - especially ones like you with chronic disease. These doctors should be avoided. But most of us are not like that; we really want to help people and try to treat them well. But we have worked very hard to earn our position; it was not bestowed by fiat or family tree. Just as you want to be listened to, so do we.

- 3 Keep your eggs in only a few baskets - find a good primary care doctor and a couple of specialists you trust. Don't expect a new doctor to figure things out quickly. It takes me years of repeated visits to really understand many of my chronic disease patients. The best care happens when a doctor understands the patient and the patient understands the doctor. This can only happen over time. Heck, I struggle even seeing the chronically sick patients for other doctors in my practice. There is something very powerful in having understanding built over time.

- 4 Use the ER only when absolutely needed - Emergency room physicians will always struggle with you. Just expect that. Their job is to decide if you need to be hospitalized, if you need emergency treatment, or if you can go home. They might not fix your pain, and certainly won't try to fully understand you. That's not their job. They went into their specialty to fix

problems quickly and move on, not manage chronic disease. The same goes for any doctor you see for a short time: they will try to get done with you as quickly as possible.

5 Don't avoid doctors - one of the most frustrating things for me is when a complicated patient comes in after a long absence with a huge list of problems they want me to address. I can't work that way, and I don't think many doctors can. Each visit should address only a few problems at a time, otherwise things get confused and more mistakes are made. It's OK to keep a list of your own problems so things don't get left out - I actually like getting those lists, as long as people don't expect me to handle all of the problems. It helps me to prioritize with them.

6 Don't put up with the jerks - unless you have no choice (in the ER, for example), you should keep looking until you find the right doctor(s) for you. Some docs are not cut out for chronic disease, while some of us like the long-term relationship. Don't feel you have to put up with docs who don't listen or minimize your problems. At the minimum, you should be able to find a doctor who doesn't totally suck.

7 Forgive us - Sometimes I forget about important things in my patients' lives. Sometimes I don't know you've had surgery or that your sister comes to see me as well. Sometimes I avoid people because I don't want to admit my limitations. Be patient with me - I usually know when I've messed up, and if you know me well I don't mind being reminded. Well, maybe I mind it a little.

You know better than anyone that we docs are just people - with all the stupidity, inconsistency, and fallibility that goes with that - who happen to doctor for a living. I hope this helps, and I really hope you get the help you need. It does suck that you have your problem; I just hope this perhaps decreases that suckishness a little bit.

Sincerely,

Dr. Rob

Avoiding PPS: A Pound of Prevention is Worth a Ton of Therapy

By Dr. Richard L. Bruno

Dear Aggie:

Forty years ago I caught a virus that killed more than half of the nerves in my spinal cord and brain stem. The nerves that survived were damaged by the virus but have been doing double the work to make up for the nerves that were killed. Even though my leg has been paralyzed for forty years, I have always been very hard-driving and am constantly busy: I work two jobs, have ten kids, take care of my 90-year-old mother and mother-in-law who live with me, volunteer at a hospital and a homeless shelter, and raise money to "Save the Whales" in my spare time. Other people who caught this virus are also very busy all the time and are having severe problems with fatigue, new muscle weakness, and pain. However, I feel fine right now-except for daily headaches. Should I change my lifestyle to try to prevent the new problems others are having?

"Symptomless in Seattle"

There has never been a longitudinal study that looks at the emergence of Post-Polio Sequelae (PPS) -- new fatigue, muscle weakness, joint and muscle pain, cold intolerance and sleep, breathing and swallowing difficulty -- in polio survivors who have no symptoms. However, each time someone surveys polio survivors, the percentage of individuals reporting PPS goes up. The first population-based study in 1983 found that 22.4% of paralytic polio survivors had PPS. The 1987 National Health Interview Survey estimated that of America's 1.63 million polio survivors, 58% who had paralytic polio and 28% who had non-paralytic polio had PPS. In England, where they don't even "believe" in PPS, 78% of polio survivors are reporting new symptoms. Something must be going on that causes more and more polio survivors to report PPS as the years go by. But what?

A 1985 survey found that PPS developed in those who were at least 10 years old when they had had polio and in those who had had a more severe infection, i.e. those who had been hospitalized at polio onset and had had more limbs paralyzed. A 1988 study found that it wasn't just the severity of the polio but how much you recovered in the succeeding years that predicted new symptoms. That is the more damage the polio virus did and the more muscle strength you recovered, the more stress was placed on the remaining, polio-damaged motor nerves. The more muscle strength you had to lose, the more likely you were to have PPS.

Then, the 1985 and 1990 National Post-Polio Surveys found that both physical overexertion and emotional stress trigger PPS. Further, polio survivors who were "Type A" (hard-driving, pressured, time-conscious, perfectionistic and overachieving) were more likely to develop PPS. It appears that both physical and emotional stress on a polio-damaged and overworked central nervous system lead to the development of PPS. This conclusion is supported by the 1991 follow-up study showing that, in individuals who already have PPS, fatigue, weakness, and pain just get worse if patients don't follow their therapists' recommendations to decrease physical and emotional stress.

So what do polio survivors like "Symptomless in Seattle" do if they don't currently have symptoms? Well, it doesn't take "Dear Aggie" or even a post-polio specialist to figure out that people with a smaller number of polio-damaged and severely overworked neurons are at risk for developing symptoms, especially if they constantly stress themselves, physically and emotionally stress. A 1997 study found that motor nerves actually die at a

rate of 7% each year in polio survivors who have muscle weakness. Doesn't it make sense to not get to the point where the motor nerves start giving up the ghost?

Will all polio survivors eventually develop PPS? Many PPS experts think so. Will all polio survivors develop all post-polio sequelae, from fatigue through swallowing problems? Certainly not. But just as people who've had a heart attack are advised to reduce stress, shouldn't polio survivors without PPS try to protect their damaged and overworked nerves?

We advise all polio survivors to follow "The Golden Rule:" IF SOMETHING YOU DO CAUSES FATIGUE, WEAKNESS, OR PAIN, DON'T DO IT!"

Why shouldn't polio survivors try to protect their quality of life by decreasing physical and emotional stress through the moderation and pacing of activities, the use of appropriate assistive devices (especially those that were discarded so many years ago), and by reducing hard-driving, Type A behavior ? Will these self-care activities prevent the onset of PPS?

No one knows. Both our patients' reports and two follow-up studies clearly show that the progression of PPS symptoms is at least halted, if not markedly reduced, when patients start to take care of themselves. So it's hard to imagine that self-care won't have some preventative effect with regard to PPS. And if prevention is possible, it would certainly be a lot less difficult and expensive than the physical, occupational and psychological therapy that are necessary to treat PPS.

What if self-care merely holds PPS off for a while, or reduces the severity of symptoms when they do occur? Or what if self-care has no long-term effect on PPS? Why should polio survivors spend their lives beating up their bodies and their spirits by taking care of everyone around them, to the point where they don't even spend a moment of the day thinking about -- let alone caring for -- themselves?

Polio survivors say, "Self-care is selfish! I feel too guilty to take care of myself." Self-care, moderation, and reduced stress have been recommended as the foundation for a peaceful and even happy life for nearly 2,500 years, since the time of the Buddha. Taking care of yourself isn't selfish, say the Buddhists, it is "The Middle Way" between sloth and excess. Buddhists say that, since compassion for everyone is the basic principle that leads to peace and happiness, people cannot be peaceful or happy if they spend their days exhibiting compassion for the whole world with the exception of just one person: themselves.

Dear "Symptomless:"

I don't know anything about viruses. But I do think it makes sense for you to start taking better care of yourself. Why is it so hard for us to take care of ourselves? Why should you be doing for everyone else and ignoring and abusing yourself? Don't you at least deserve not to have your head hurt all the time? Why don't you start by doing one thing for

yourself for each thing you do for someone else? Maybe you won't prevent new physical problems. But the worst that could happen is that other people will still be helped and you'll feel better. Why should you "Save the Whales" and not save yourself?

Aggie

Mourning Glories *By Millie Malone Lill*

Grief comes in stages: Denial, Anger, Bargaining, Depression and finally Acceptance. As I've told friends who've lost loved ones, we all go through these stages and it takes as long as it takes. We polio survivors also grieve for our lost abilities, and in much the same way.

When I first started to suffer from PPS, I was in denial. Nonsense, polio happened eons ago when I was a child. I'm fine now. Of course, I fell a lot and I always had a bruise coming or going. That was because I was a klutz who tripped over her own shadow. I was told that I needed to go back into a brace. WHAT??? No, I don't think so!

Finally, the fact that my ankle turned over so often that a callous formed and then split convinced me that maybe I should get a brace. I was not happy about this. I had gone through surgeries so that I would never have to wear a brace again. How dare they say I needed this! How dare this even happen to me! I'd worked so hard with the dreaded Physical Terrorists, did the painful exercises religiously, went dancing, skating, swimming, all to conquer polio.

I had reached the Bargaining stage by this time: I'll wear the stupid brace if you insist, but only when I have to walk on rough ground. It's ugly and it doesn't fit in my shoe. In fact, it is attached to a pair of those ugly shoes I swore I'd never set foot in again. I want to wear pretty shoes, like other women!

After wearing the brace awhile, I discovered that the callous on my polio affected foot no longer split and filled my shoe with blood. I'd long ago learned to ignore that pain, so I was surprised at finding it gone. I wasn't falling so often, either. I still lurched into doorways but not as often. That was good, but those shoes. Oh, those ugly, ugly shoes. I felt like an old woman, no longer young and fashionable. I would never wear dresses or shorts again, because then people could see the Hated Brace. I was almost sick at heart. I'd really tried so hard to overcome my disability and darn it, here it was, back again. This time in so visible a form that there was no hiding it.

Gradually, I accepted the brace as the tool it was meant to be. I could walk across the field to bring my husband his lunch when he was working there. While doing chores, I could carry the milk into the separator room without spilling it. I found nice looking dress pants to wear when I dressed up. Gradually, I even grew brave enough to wear dresses and shorts again. Summer in Iowa is a great motivator for wearing something cooler!

Then it happened. Hurrying around to get dinner ready by the time my husband came in from the field, I stepped on something on the floor. Down I went, my body twisting over the Hated Brace. I got a spiral fracture in my polio affected leg. Rats. Back to square one in the Grieving Game.

This could not be happening! Oh, no, that leg won't bear weight. I'm back to crutches, and a manual chair. It took 18 months for that leg to heal enough that I could walk on it. Meanwhile, I'd lost what little muscle tone I had and could no longer lift the leather and steel brace I'd finally accepted. I had to find a brace light enough for me to be able to lift my foot, yet strong enough to keep me from falling.

Weeks, months, and years went by while I struggled to stay out of the power chair that was looming large. On one memorable visit to my polio doctor, I got a real slap upside my head. A rude awakening, if you will. I found I absolutely could not walk from one end of the hospital where my doctor was to the opposite corner where my orthotist worked. I claimed one of the hospital's manual chairs and got another good Wallop of Wisdom. I couldn't push myself in that chair! You know I tried, I am a card carrying polio survivor and we always try. I managed somehow. When I finally got back in my car for the drive home, two hours away, my head was buzzing with fatigue.

I knew I'd have to give in and get a power chair. My doctor had no problem prescribing one for me and a friend of mine ran the Durable Medical Equipment place in town, so very soon I had a power chair. Would you believe I had to go, again, to the beginning of the grieving process? The chair sat there. I refused to use it. My friend, the one who'd sold it to me, asked why I wasn't using it. I told her it made my back hurt. She looked at me with that look your Mom gives you when you try to tell her a story. She whipped out her tools, adjusted the back of the chair and told me to plop my behind in it and not to be so stubborn.

It's too late to make a long story short, but I did finally accept the chair, got a ramp installed on my house, put a lift in my van, and discovered freedom. I could now go to the post office or the store without pain and exhaustion. What a concept! I could go to the zoo! I've always lived within driving distance of the Henry Doorly Zoo in Omaha, but I'd never been there. I discovered a whole new world of things I could do now that I had wheels.

I've moved since those days and I've replaced that chair a couple of times. I now live in an accessible building and can take my power chair to the park, to the grocery store, to the library, to my dog's vet, to the movie theater...and if I want to roam farther, I can load it in my van and go some more. Once I moved through all the stages of grieving for my lost abilities, I found that life is really good. It just takes as long as it takes.

The Web Corner

Crutches for Comfort and Good Looks:

<http://www.smartcrutch.com/>

High GI Leads to Food Craving, Study Says

<http://blog.joslin.org/2013/08/high-gi-leads-to-food-cravings-study-says/>

A Not-To-Do-List For the Chronically Ill:

<http://www.psychologytoday.com/blog/turning-straw-gold/201308/not-do-list-the-chronically-ill>

Back Pain Remains Overtreated

<http://well.blogs.nytimes.com/2013/08/02/back-pain-remains-overtreated/?emc=eta1>

Water Skiing For People With Disabilities

<http://ucanski2.com/>

Ten Things Every Parent Should Teach Their Kids About Disabilities

<http://www.themobilityresource.com/10-things-to-teach-your-kids-about-disabilities/>

Gastro-Intestinal Involvement in PPS

<http://www.poliosurvivorsnetwork.org.uk/archive/lincolnshire/library/usa/gi.html>

Reasonable Accommodation And Undue Hardship Under the ADA

<http://www.eeoc.gov/policy/docs/accommodation.html>

Post Polio Support newsletter

<http://www.eeoc.gov/policy/docs/accommodation.html>

Dancing on Crutches

<http://www.upworthy.com/happens-every-time-watching-this-dude-kill-it-on-the-dance-floor-makes-my-heart-burst-open>

A Little Bit of Humor

CAR KEYS (The Golden Years)

Several days ago as I left a meeting at a hotel; I desperately gave myself a personal TSA pat down. I was looking for my keys. They were not in my pockets. A quick search in the meeting room revealed nothing. Suddenly I realized I must have left them in the car. Frantically, I headed for the parking lot.

My husband has scolded me many times for leaving the keys in the ignition. My theory is the ignition is the best place not to lose them. His theory is that the car will be stolen.

As I burst through the door, I came to a terrifying conclusion. His theory was right. The parking lot was empty. I immediately called the police. I gave them my location, confessed that I had left my keys in the car, and that it had been stolen.

Then I made the most difficult call of all, "Honey," I stammered; (I always call him "honey" in times like these.) "I left my keys in the car and it's been stolen."

There was a period of silence. I thought the call had been dropped, but then I heard his voice. "Are you kidding' me", he barked, "I dropped you off"!!!!!!

Now it was my time to be silent. Embarrassed, I said, "Well, come and get me." He retorted, "I will, as soon as I convince this cop I didn't steal your car."

Yep it's the golden years.....*