
MY LIFE WITH REBECCA: HOW A HUSBAND LIVES WITH HIS WIFE'S EI

by Bob Brunk

Dealing with environmental illness is not simple. But life, in general, is not simple. Life is tough. You can see that by reading the newspaper. If you accept that, it puts things into perspective: All of us have problems, but it's the way we deal with them that determines whether they're hard or not.

Perhaps the most important thing I had to do when my wife, Rebecca, became ill was to *accept the reality of the situation*. That wasn't as simple and obvious as it seems. Denial is easy for both parties. We know people who have stopped their spouses from seeing a doctor. Most of us would think that absolutely ludicrous, but it happens. I never stopped Rebecca from going to the doctor, but in the beginning my attitude was, "If the insurance will pick it up, go on and see a doctor, but I'm not convinced any good is

going to come of it." What I had to do was to accept the idea that EI is a very real illness, in the same way that heart disease, diabetes, and cancer are real illnesses.

Then I had to realize that *it is impossible for someone else to fully relate to the problems of a person with EI*. Not surprisingly, this works both ways. It is equally impossible for Rebecca to truly relate to anybody else's problems. She's sensitive to so many things that she cannot possibly relate to what I'm going through because she isn't living it. Even though we're as close as we can possibly be, her life is quite different from mine — and mine from hers.

Once, while we were on vacation in Hawaii, I got mildly sunburned. Two days later, while on a boat ride, the sunburn began to itch unmercifully. We raced back to the hotel, where a shower provided temporary relief. Drying off started the itching again, so I spent hours in the shower. We ended up at the hospital emergency room that night. That was one of the worst experiences of my life, but it showed me firsthand what it's like for a person who can't control something that's causing pain and discomfort to his or her body. It also showed me that no matter how close I was to Rebecca's situation, I could never be close enough to it to relate totally.

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In dealing with severe sensitivities and EI, *it's important to understand the nature of the beast*. This means accepting the seriousness of the problem. Severe sensitivities can sometimes be life-threatening — most of us have heard of people who have died from bee stings. It's equally important to understand that when someone is having a reaction, emotions can come into play every bit as much as rashes, coughing, wheezing, aches, or pains.

I learned, too, that I had to accept the idea that there were going to be some difficult moments — inconveniences, awkwardnesses, embarrassments. About a year ago, for example, we got on an airplane and found ourselves seated among people so loaded with perfume that Rebecca couldn't stay there. That was hard for me to accept at that moment, but the next thing I knew, she was having an asthma attack, and we were pulling out the oxygen to revive her. Suddenly, my own awkwardness took second place. A few instances like that cause one's own self-consciousness to lose significance.

(I do want to underscore the idea that chemical sensitivities should not be used as an excuse to impose on people unnecessarily. I have seen people do that in order to assert their own importance and take control of a situation. Having such an illness does give you a certain degree of power, but it must be used judiciously.)

Another thing that I've come to realize is that *sacrifice is not martyrdom*. I've learned that, if you want to, it is possible to change without trauma. It's so easy to say, "Poor me — I've got to take care of my wife." People often look at

me and say, "Gee, how do you deal with this? This has got to be every bit as hard on you as it is on her." Well, it's not. It's definitely not. And we do a lot of adapting. I made up a little rhyme that I say to myself: Don't patronize or sympathize, but understand and lend a hand.

Here's an example: Rebecca is very sensitive to dogs, but we had a dog that was like a child to us. How do you resolve a situation like that? You end up making compromises. The dog stopped sleeping in the bedroom. She slept in the basement, and Rebecca stayed out of the basement. I knew that when the dog was gone, we wouldn't get another. I accepted that, and that's what has happened.

The final point I want to make in discussing attitudes is that it's important to *make a commitment*. Half-hearted support doesn't really mean much to anybody. That's true not just in terms of EI but in terms of anything. I don't know how many times someone has said to Rebecca, "I knew you had problems with perfume, but I didn't figure my little bit was going to hurt you." That's not support — that's half-hearted. On the other hand, a while ago we dined with some friends who prepared a lovely meal without consideration for Rebecca's allergies. At the same time, however, they provided Rebecca with a different meal, serving her a complete and delicious dinner that she could eat. That's what I call support.

It's been my experience that the less support you give the person you're dealing with, the more anger you will feel. At least that's true for me. Refusing to give support builds walls between people, and those walls cause the deepest kind of pain. If you're married, remember your marriage vows. If you're not married, think about what you're going to say if and when you do get married: "In sickness and in health . . . till death do us part."

So far, I've been discussing attitudes and the importance of having the right ones. Now I want to touch on the actions that follow from those attitudes. The first thing you want to do is to *get fully involved*. You can't just dump the problems of the person you live with back on that person's shoulders. If that person says "Help me, I'm having a problem," even if only with his or her eyes, it's time to respond. That person needs you.

We must realize that we have to work on protecting our loved ones with EI, because they can't always protect themselves. We recently ran out of our usual "safe" dishwashing liquid. I had to get another brand at the store, and Rebecca reacted to it. I ended up washing dishes that night, a job that I hate more than almost anything else in the world. Rebecca knows this, so when she saw me doing the dishes, it really meant a lot to her. It made her evening a lot easier, too, both because it showed her that I cared about her and because it helped her to avoid further reactions.

The second thing you will find yourself doing is *adapting your lifestyle to fit theirs*. The key word is "adapt." This is not a matter of denial but of modification, so as not to exacerbate existing problems. In our house, for example, we no longer buy mushrooms. I love mushrooms, so what do I do about that? I get mushrooms whenever I go out to dinner. When I go out of town, I really load up on them.

The third thing I've found that makes life much easier is

to *plan ahead* — and *plan together, not apart*. We plan very carefully, for example, when we should go to movies. We try not to go on Saturday nights, when the theaters are crowded. When we go to restaurants, we phone ahead to find out what the menu is like, whether there's a nonsmoking section, and so forth. That kind of planning minimizes problems.

I've also had to learn to *be flexible*, to bend and blend my own wants and needs with the things I can do with Rebecca. If we're out somewhere and want to stop for lunch, we're going to stop where we can eat together. I don't head for McDonald's and leave her on her own to find a place to eat.

On the other hand, I think it's necessary for anybody involved in a long-term support relationship to *retain something that is yours*. Golf happens to be my thing, so I periodically play a round or hit some balls. It's important, I think, to do things like that, because if you don't retain something that's your own, you run the risk of falling into the martyr syndrome.

I also think that it's important for the support person to *get involved in the medical aspects of the illness*. I think it helps to play an active role in determining what causes reactions. It can bring you closer together as a couple, and you might be amazed at how interesting it can be. If you've ever read or watched murder mysteries, diagnosing chemical sensitivities and allergy responses will seem familiar. It's detective work.

It's good to *develop a sense of humor about things*. A little light banter can help a lot. Sometimes, for instance, when I feel that Rebecca's getting too wrapped up in things, I tell her that if I fell down the stairs and broke my leg, she'd say I was allergic to the stairs. Whenever I come out with that, she understands that I'm asking her to lighten up a bit.

Finally, the critical key is to *love them*. When times get tough, you'd be amazed at how much good a hug or a kiss will do.

In conclusion, I'd like to mention how I've benefited personally from dealing with Rebecca's EI. Because we have worked together in this, I believe that our marriage and family life have been strengthened, that her illness has drawn us together instead of pulling us apart.

I've learned the importance of looking to the future. If you truly support each other, you can indeed make it through the tough times and look forward to better times ahead, and that's hope. As a side benefit, I've learned something about what good living is really all about — what it means, for example, to eat truly good food that's simple and well-prepared.

In addition, I've learned a lot about myself. I don't think that it's possible for anybody to go through these kinds of problems and not learn from them. I've learned things about myself that I like — and some things that I don't like. And I've learned a lot about family life, about love, compassion, and understanding.

The best part is that if you show those qualities, you get them back in return. Sometime after Rebecca developed EI, I went through some problems of my own with a difficult job change. Rebecca was really there for me — and I wasn't always such a nice person to deal with, either. I found that

giving support to someone I loved became a two-way street. I ended up getting benefits totally outside the world of allergies — benefits I never knew I'd have.

I don't mean to imply that Rebecca and I have our act totally together — I don't think that anyone ever can accomplish that. But what I do mean is that we're working on it. And if anyone else who reads this is encouraged to work on his or her situation, too, then sharing our experiences has done some good. □

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