



Podcast Transcript:

Dr. Ron Falk

Living with ANCA: Healthy Behaviors

Dr. Falk: Let's discuss what things you've done to take care of your body and your mind. You've done all sorts of things. So what do you think are good, healthy behaviors that you've learned over these 14 years?

Dianne: I think that you have to embrace a sense of wellness. To constantly think of yourself as sick is not helpful or healthy. So you really need to think of yourself as a well person.

You need to eat well. One of the patients I talked with said that when she isn't feeling well, when she feels she might be going into a flare, she really tries to work on her diet—ie no sugar, no caffeine, no alcohol. Another patient told me that at that point she tries to eat more fish or chicken, less red meat.

Exercise is very important. I know it's hard when you're not feeling well and in my case, is hard because my airways aren't great, but find something to keep yourself moving. One woman who has joint problems, for instance, does swimming. Exercise helps you physically but it also helps you mentally, because it gets you out of yourself, it gets you out of your mind. Two of the things that I do, are yoga and meditation—both of which help me a lot. I also walk.

Dr. Falk: So, let's talk about one other thing that many, many patients do and you've already alluded to it—the afternoon nap. Fatigue is hugely part of this disease, as it is with any autoimmune disease. The tendency of some people is to try to push through that fatigue. I think it might be almost impossible to do that at certain times.

Dianne: It is, and I think that's one of the hard things about this disease is to accept limits. Know that you will reach them. You have to think of things like an energy bank. Know that if you're going to make withdrawal, ie, go to a concert, or an event, you have to make a deposit, ie a nap. So planning ahead, knowing you're going to have a really active weekend-get extra rest. Or build in some downtime

that weekend so you can get a nap, or just put your feet up so you're not constantly on the go and wearing yourself down.

Dr. Falk: Does that help with the physical parts of this disease as well as the mental ones?

Dianne: It does, because when you're tired it's just not good emotionally, mentally—you're more fragile, you're more prone to be moody and sad. So it's just very stressful and frustrating when you're really tired. So finding a way to cope with fatigue is very, very important.

Dr. Falk: When you first started, many years ago, you were really worried about needles. If you recall, the thought of having a blood draw was almost insurmountable at one point in time. That turns out to be a pretty common fear. But everybody has an anxiety about one thing or another. How did you deal with your needle phobia? You certainly have dealt with it remarkably well. How would you help patients in general deal with anxieties that occur, just as part of their daily life, or part of the medical routine?

Dianne: For my needle phobia, which I still have, when I have my blood drawn, I still have to lie down. They always sort of look at me... "I know I've done this before, I know you've drawn my blood a hundred times, but I have to lie down."

The first time I had the problem, I went to see a friend who was a psychologist. I said, "Help me with needles, because I'm phobic about this, and I'm going to have a lot of needles." He told me to try to take myself somewhere else. So I tell the person who's drawing my blood, "Okay, you just say 1, 2, 3 and I go to the beach." And I don't look, and then they say, "Okay it's over."—and then it's over.

I think you need to figure out the things that stress you about your medical care and your life, and try to find ways to relax or to cope, because these things aren't going to go away. You've got to figure out a way to get through them and cope with them.

Dr. Falk: What would you do if you can't get through those? Let's expand on that whole psychological help sphere. What would you advise people with respect to seeking psychological help?

Dianne: I feel like a lot of people think that they need to get through this alone, that they're strong, they're tough, they can handle it. But at a certain point some people do get depressed. You actually saw that in me and sent me to someone and it helped enormously. I think that people think it's a sign of weakness if you have to get help. It's

not at all. I think counseling, or talking with someone impartial, you can really clarify the issues, with someone you can be completely honest.

I think most patients tend to shield a certain amount from your family, from your friends, but with a counselor you can open up and be really, really honest, and take off that brave face for a little while and really talk through the issues that you're facing, and figure out ways to work with them.

Dr. Falk: I almost think that everybody who has a chronic illness, especially one that relapses and remits, needs some kind of counseling and intervention. I don't think it needs to happen from a psychologist or a psychiatrist. It does need to be somebody who is separable from your nuclear family. It could be somebody in a church, somebody who has other kinds of training, just so they can help you through those moments of sadness or anger.

I can't imagine anybody who has one of these diseases, who, several months prior to having a diagnosis was completely well, who isn't somehow disturbed by what's happened to them. Especially with the disease process that we can't use the word "cure". We can use the word "long-term remission" but that's got to bugger up one's brain.

Dianne: It does. Someone very wise wrote a book called "A Whole New Life." It's by a man named Reynolds Price, a cancer patient, and he was talking about making a whole new life. I want to read just a little bit:

"Generous people, true practical saints, are waiting to give you everything on earth. But your main want, which is simply the person you used to be. But you're not that person now. Grieve for a decent limited time, or whatever parts of your old self you know you'll miss, have one hard cry if the tears will come. Next, find your way to be somebody else, the next viable you. A stripped-down, whole other clear-eyed person."

Dr. Falk: Reynolds Price is a wonderful writer, so that's an incredibly eloquent description of what needs to happen. Those words, even though they apply in Reynolds Price's case of somebody with a cancer—apply to anybody who has a serious medical condition that's not immediately going to go away.