Podcast Transcript:
Dr. Ron Falk
Living with ANCA: Finding your New Normal

Dr. Falk: Let's go back to this concept of finding a "new normal." How practically do you find a new normal? How do you figure out when you go back to work, how do you make the decision? How do you go about that whole thinking process?

Dianne: I think you have to consider your body, your illness. I think you need to talk with your physician, and with your family. I know one patient who was also taking care of her ill mother. She decided that between that stress and time commitment and her full-time job, that the best thing for her health would be to retire. And she did. Other people may decide to go on disability. I think you have to see what's going to work for you and what's really important in your life. One woman said, "I know with disease, it's going to limit my life somewhat. So with the time I have left, how do I want to spend it? What's most important to me?" And that's the question that you need to ask. If you have to work, then try to work it in your job so that it's doable for you. Or you may consider changing careers. Or do something part-time.

Dr. Falk: How do you help your spouse find the "new normal"? When one person has a chronic illness, the spouse also must find the new normal. What's the way that you get your spouse, to help them not to feel pity, but to be there when they're needed. So many issues around spousal "new normal."

Dianne: I think the first thing that patients need to think about is that it is okay to accept help. It doesn't mean that you're a weak person. People who are around someone who is ill, they want to help. I think letting a spouse help you is important. You don't have to do this alone—it's impossible to do alone. I think getting over that hurdle of "He's busy, I don't feel like I can ask him that." You need to understand that helping is something that helps not only you, but the person who wants to help you.

I think in terms of a new normal, it's learning to compromise together. It's learning to say, "Well, it would be great if we could do A, B and C but, you know, maybe I could do A with you, and maybe you could do B, and I could join you for C." It's working out what's going to keep you in your best condition, but also keeping that relationship strong and viable.

Dr. Falk: It doesn't just apply to the spouse, it also applies to kids. Children, especially of moms who are ill. It seems that persistent worry that Mom won't be there for the kid, they won't be able to participate in whatever activity they would normally be able to participate in. It seems as though parents need to give themselves permission to perhaps be less frenetic, and get to some events but not necessarily all. The goal needs to be for the kid to see the parent as they grow up over time, not necessarily for each individual activity that parent would normally go to.

That's probably, from what I've observed, one of the biggest new normals—the guilt of the parent not being able to participate in the kid's activity, the fear of the child that their parent isn't necessarily going to make it—"How come Mom or Dad isn't able to be here?"

The more worrisome thing in adolescent kids is the concern of, "Why is this happening to my parent? Why isn't it happening to somebody else's parent?" And the anger that goes along with that. Especially in adolescent children whose parents have this disease, I've encouraged that adolescent to get counseling very early on.

Dianne: One patient told me that her child was supposed to read to her at night, and there were nights when she was just so exhausted she couldn't do it. So she had her daughter call her grandmother, and that was how the reading got done at night. It was a way to get it done, that way the patient didn't have to do it, but she could sit there with her daughter while it was going on.

Dr. Falk: If it's not a member of the family, that's a great thing for a friend to come and do. Just being there at certain times and important times, and knowing when to leave, are useful things as well.