



UNC
KIDNEY CENTER

Podcast Transcript:

Dr. Ron Falk

Fibrillary GN

“Fibrillary GN: How can I deal with feelings of frustration and loneliness?”

Patient: I’m feeling very alone and frustrated lately. I used to be perfectly healthy. Now I suddenly have this disease that nobody’s ever heard of. What can I do to feel better about this?

Dr Falk: That’s a spectacular question, and one that’s very hard to deal with. Any disease that has the term “idiopathic” or “unknown” implies that we don’t understand the cause of the disease. Fibrillary GN is but one of those. So when your physicians and the medical community don’t understand what causes the disease, and know very little about how to best to treat the disease, this can be a most frustrating and lonely experience.

I think that the very fact that you’ve asked this question suggests that this kind of open conversation is most useful and most healthy.

Many autoimmune diseases, many diseases that affect the kidney, occur out of the blue, and a perfectly healthy person is now struck by something that barely has an understandable name, but clearly has an unfortunate consequence. That’s very hard to adapt to, no question about it. It would be easier if one was in a car crash, that would be understandable—the length of therapy would be relatively clear and the hope of getting better would be reasonably understood. Autoimmune diseases, diseases like yours don’t necessarily have this kind of precision.

My best advice is to keep this kind of open conversation, to try to maintain a most normal life as humanly possible, to exercise, eat well, and enjoy each and every day—not to think as much as possible about the long term, but to enjoy today as a wonderful day. The expression of “live for today” is reasonably a good approach for you and your disease.

I think the other important thing to do is to make sure that you have somebody at home or in your community to talk with about your loneliness and about your frustration. We suggest counseling for almost everybody with an autoimmune disease, just to help get through the absolutely understandable frustration and loneliness of having a disease

named after a specific pathology. And figure out ways to adapt. I would encourage you to try to undertake your lifestyle as you normally have. Once patients end up on dialysis or require a transplant, there are better orchestrated approaches to trying to deal with dialysis or the work-up of a transplant.

The good news is that some patients with this disease get better all by themselves. Some patients with your disease have the disease process, some protein in their urine, but never get worse. Then there's always the prospect, if your kidneys fail, of having a transplant without a huge possibility of recurrence of the disease. All of that is very helpful.

I think that hope is what is most important to hold onto, to help with this loneliness and frustration.