



## Approaches for Coping Day-to-Day With an MPN

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**Beth Kart Probert:**

Coping, and that was a big question for myself, too. How do I cope with this? What do I do?

So I'd like to start off with asking for help. And, Dawn, if I can ask you, in the role of the nurse, I imagine, and in my relationship with my nurse, that you are giving out a lot of advice about coping. Could you talk to us a little bit about some of the things you tell your patient?

**Dawn Urbanovsky:**

Patients, most frequently, will complain a lot about fatigue as one of their symptoms. So I tried to encourage their efforts to be more active, try to get some exercise, start small, start walking, and encouraged that kind of thing, because that really does make a big difference with that particular symptom. And then, be open and listen to what they're saying and address each symptom individually and make recommendations. And also, knowing when to elevate that to the rest of the team, because, possibly, there are some other things that can be done.

We have other clinics in our facility. We have a fatigue clinic. We have pain clinics. And so, we can get them in touch with other clinics that can help them address those symptoms and improve the quality of life.

**Beth Kart Probert:**

Wow. And I'd like to ask Dr. Yacoub, at the University of Kansas, do you have some different facilities or things that your team also helps patients with coping?

**Dr. Yacoub:**

Excellent. So in addition to everything that she mentioned, if you take a normal person without MPN, and you ask them to be on the right diet and exercise regularly, they will feel better. So that is a ubiquitous and universally beneficial strategy. So we could start with that basics and implement that as much as possible. In my clinic, there's an integrated psychology service, an onco-psychologist.

And I insist. There's a stigma where people do not necessarily want to meet the psychologist. But this is a sub-specialized onco-psychologist who is in my clinic all of the time seeing every single patient. And I insist on the meeting, and I insist on at least one more follow-up after my clinic one to one, because some patients will have needs that they will find a great help from that service. So that's something that is, I find, very helpful. And, also, in addition, so a lot of those symptoms those patients are having are actually disease related. The fatigue is not just tiredness. It's the disease.

And a lot of the itching and night sweats disturb your sleep and cause you to be depressed. And there are a lot of organic symptoms. So, also, optimizing the cancer treatment can be of improvement in the way you cope with your disease is by feeling better, in general, will elevate your health.

So these are the two strategies that I implement or try to as much as possible.

**Beth Kart Probert:**

Wow. And that's a really unique touch with the onco-psychologist. And I believe, earlier, you had spoken about— Julie, you had spoken about doing some other kind of strategies. And we hear a lot about mindfulness. I certainly researched mindfulness when I was diagnosed. What is it? And would you happen to have any feedback about that topic, mindfulness and what you can tell patients to do to not stress out?

**Julie Huynh-Lu:**

One big thing that I find that is helpful is yoga. I find that I can convince women to do it more than men. I have some men that complain also of bone pain, which is a symptom of MF primarily, but they can have it with ET/PV sometimes.

And I always say doing yoga can help kind of center themselves. Doing mental exercises where you're not on a tech device, on the phone, on the TV, on the computer and just have a few minutes to just sit by yourself and just think for yourself and just calm your mind down. So I think that's a big component. Also, diet and exercise. I see that on there, and I know we've all mentioned it quite frequently. So if you guys don't get anything out of it, diet and exercise are important. I sometimes have some patients that come to me, and they're complaining of fatigue and just feeling really cruddy.

But they're eating chips, and they're eating ice cream daily. They're not getting their daily vegetables. And they're not eating adequate protein. Their exercise is limited to I get up from the couch, and I walk to the fridge, and I come back.

Or I get up, and I go to work, and I'm walking. But at work, sometimes, we're sitting primarily. So when is an opportunity for you to exercise? Sometimes, even on a lunch break, I have patients that just walk up and down the stairs in their hallway at work. So I think that's a way to just incorporate into your day, if you just don't have time in the morning or in the afternoon when you're just hey, I've got to prep for family. I have to cook dinner for my kids, things like that. Just finding ways to incorporate that into your work life can help time-wise, if you didn't have the time.

**Beth Kart Probert:**

Samantha, you talked about I think you spoke about night sweats. How did you cope with that?

**Samantha:**

Night sweats are not pleasant, because you don't get enough sleep. You need to be well rested. I will tell you, I try to exercise every day. I eat a very clean, plant-based diet.

I try to get eight hours of sleep every night. I find that these things are critical to my ongoing health. And I'm very protective over that. Night sweats come and go, and they interrupt your sleep pattern. They make you feel gross. You need a second set of pajamas. And you just don't feel well. And I think that to bring that up with your medical team, see what other options they have for you, because, while it seems like it's no big deal, oh, you sweat at night, it is a big deal. And it interrupts your day. And it interrupts how you feel about yourself and your overall health.

**Beth Kart Probert:**

Absolutely. And that kind of brings me to some cognitive issues. So you're up during the night, maybe because you're sweating. We talked about this. Dr. Yacoub said you're not getting your sleep, or you're stressed out, or you're worried. It could lead to depression. But, Andrea, I wanted to ask you, did you ever deal with, because you've had a long journey, did you ever deal with some cognitive issues, meaning that I just can't think straight? And if so, how did you handle that?

**Andrea:**

Well, those issues, it's hard to determine whether they're age related or whether they're disease related. I guess I'm on the mantra of diet and exercise and sleep. If I don't get enough sleep, I feel the cognitive issues. I retired early for many reasons, part of which was the disease. I didn't want to work myself into the grave. And I ended up going back to work. I did many different jobs. I worked in a bike store. I went from corporate America to a bike store. And now, I work at Apple. And I find that that really helps cognitively because it gives me mainly the satisfaction that I'm doing something productive for myself. And what everyone does is different. Even reading a book is fine. I am in two book clubs.

I really try to keep connected with people, and with young people, in my case, because they really help me understand what's going on. I like to be connected. I always thought I was connected, and then, I got around them and realized how disconnected I was. So that really helps my cognitive makeup, if you will, and keeps me sharp as I can be and going.

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