



## How Do I Know If My MPN Treatment Has Stopped Working?

**Srdan Verstovsek, MD, PhD**

Chief, Section for Myeloproliferative Neoplasms, Department of Leukemia  
The University of Texas MD Anderson Cancer Center

**Julie Huynh-Lu, PA-C**

Physician Assistant, Department of Leukemia  
The University of Texas MD Anderson Cancer Center

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**Beth Kart Probert:**

So, Dr. V, I'd like to ask you this question. How do I know if a treatment stops working if I'm under treatment for something?

And what should the signs be that I look for to communicate with my doctor? And how would I even know if my treatment is not working?

**Dr. Verstovsek:**

So this is very important, because we have mentioned several times already that there is a team in place. And the patient is part of the team. Education that was highlighted already is part of the efforts on our part to educate the patient. But the patient needs to also, because these are chronic conditions, get involved and learn about what is this all about, what condition do I have? I'm going to live with it for as long as I can. Hopefully, as long as I can means nine decades, 10 decades. But meaning that you have to participate and learn why you're being treated. Doctors will tell you about it. Doctors will tell you what the goals are.

Your understanding of the condition and the therapies will help, in your own management, over the year to come. So if you are on a therapy to decrease the risk of blood clotting that is the goal for patients with high platelets, ET, or polycythemia vera, then, there might be some benefits and possible side effects of those therapies.

Benefits would be improving the quality of life, eliminating symptoms from sluggish blood flow, eliminating perhaps an enlarged spleen or itching, and elimination of the phlebotomy for patients with polycythemia vera. But there might be some fatigue from the therapy, some loss of hair or some diarrhea. So, knowing and discussing your quality of life and your issues as you are being treated with the team, starting with Dawn and Julie and myself as a team, or in any other situation where you are, is imperative for us to provide the best possible care all together. So, knowing what to expect and asking questions and being engaged is a priority for us.

**Beth Kart Probert:**

I definitely can imagine that it really wouldn't work well with us saying this is happening and this is not.

And, Julie, I have a question for you. I know I see my doctor every four weeks. And I think, talking to people in the room, there's different timeframes. But what happens if I started a new medication or something comes up? Could you just give me an example of how you would communicate with a patient or what you would tell them between doctor visits because it could be crucial if I wait four weeks to talk about a symptom I might be having?

**Julie Huynh-Lu:**

So, usually, once we start a patient on a new therapy, we don't just say, hey, we'll see you in six months. We usually have them come back in a few weeks either to do a blood draw or just to see us to see what's happening with our account, see how they're feeling. But I don't know how it is at other hospitals. But we have a My MD Anderson account that patients can send us a message either to Dr. Verstovsek, myself, or Dawn. And it's a 24-hour turnaround, or they can have Dr. Verstovsek loves to give out his card. You can call him at any time.

He will answer. He will call you back. I'm never in my office, which most of you guys probably know because, when you call me, I never pick up. But it sends me an email right away that says this person called. So those are just ways of letting me know something happened, or something changed after you started the medication, because, sometimes, someone will say gosh, I just feel so fatigued now. I feel nauseated. Well, I want to know that so that I can bring you in sooner rather than in four weeks like you said.

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