



Tips for Controlling MPN-Related Fatigue and Itching

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Andrew Schorr:

Andrew Schorr in London with a noted hematologist from London, Dr. Jon Lambert from UCH, or University College Hospital in London.

Jon Lambert:

That's right, yes.

Andrew Schorr:

And one special area of interest for him is helping people with MPNs. And, Dr. Lambert, fatigue is a big one that people complain about. We'll talk about some other side effects of the illnesses that affect people, but fatigue, everybody I talk to—fortunately I haven't had it yet with myelofibrosis, but so many say, I'm just tired. What do we do about that?

Dr. Lambert:

That's a very good question. I mean, fatigue is probably the commonest symptom in patients with all myeloproliferative disorders. We used to think it was more associated with myelofibrosis, but actually polycythemia and essential thrombocythemia patients are often commonly affected by fatigue and it's a symptom that we as doctors are not very good at treating.

I think it depends on each individual patient what the cause is. It can vary. Sometimes it's related to the underlying disorder, sometimes it's the treatment. So the most important thing is to have that conversation with your physician to try to identify, A, how bad it is and what, you know, whether it is having a significant effect on your quality of life and, B, what the possible cause might be. So obviously if it's related to the treatment—hydroxycarbamide (Hydrea), interferon, they can certainly cause those kinds of symptoms—you may want to have a discussion about changing either the dose or changing to a different treatment. If, though, it's related more to the actual underlying condition, then there's a number of different things that can be done, but they don't all work in each patient so it's a matter of trying to work out what's going to work best for you. So, for instance, in some patients with myelofibrosis in particular but also other conditions I find that a graded exercise program can be very effective. Certainly the evidence from that comes more from teaching patients who've got solid cancers or have had chemotherapy from that, but in my experience it can work very, very effectively in people who've got myeloproliferative disorders and have got fatigue related to that. So, for instance, a graded exercise program, five, 10 minutes a day of moderate exercise, and moderate exercise will vary from person to person depending on their age and their fitness, but just enough to get the pulse up a little bit can be very effective over time. Certainly studies show it is effective in increasing energy levels, reducing fatigue and improving general fitness as well.

Andrew Schorr:

I want to make sure I got this right. So somebody says to you, I'm tired, and you're saying, you need to exercise?

Dr. Lambert:

Yes.

Andrew Schorr:

It sounds counterintuitive.

Dr. Lambert:

It does sound very counterintuitive, and one of the odd things about fatigue we see in myeloproliferative disorders, it's not like normal tiredness where if you go to bed, have a good night's sleep, the following morning you feel refreshed. Sleep is not refreshing, and actually you've got to get into this vicious circle where—and potentially you're doing less activity because you feel tired and then actually that compounds the problem, so the solution is not to do less. Now, obviously you need to talk to your physician and get an idea from them as to whether, you know, you're fit enough to start doing an exercise program, so that again requires a conversation, but certainly I would never say to a patient just because they're feeling tired you should be doing less. My recommendation is usually to do a little bit more. If you're doing so much exercise that you feel shattered and exhausted the following day, that's too much. But just a little bit, five, 10 minutes a day, even if it's just a brisk walk, but then the second stage is also to slowly try to increase what you're doing on a week-by-week or a month-by-month basis. So that involves keeping a diary or a record of what you're doing so you can then look back and say, last week I did five minutes a day, this week I'll do 10 minutes a day. So that can be very effective but, again, it depends on the individual and they've got to have an underlying mobility to be able to do that, so it doesn't work for everybody.

Andrew Schorr:

Dr. Lambert, we don't have to get into all this now, but, as you know, some patients have itching. Some people have difficulty even bathing sometimes the itching is so bad with the water. Some people get headaches and then, of course, the tiredness as well. It sounds to me the bottom line is try to connect with a physician that you trust who's knowledgeable in the MPNs and have a personalized discussion.

Dr. Lambert:

Yes. As I say, these conditions vary dramatically from person to person and the different people are caused by different things. It's a matter of trying to find what the trigger is. For instance, with itching sometimes it can be water, hot water, but in some people it can be something completely different. And we know from studies that different treatments work differently in different people, so for some people it may be an antihistamine, for some people it may be a simple non-steroidal analgesic. In other people it may require something like a JAK inhibitor which can be very effective in a number of these more sort of difficult to treat symptoms, but they are very individualized and it's very much a matter of, well, one solution doesn't fit all. You need to have that discussion and come to a personalized management plan that suits you, understanding that sometimes it's a matter of trying one thing, seeing if that works, if that doesn't work, trying something different. It can be very difficult.

Andrew Schorr:

Okay, so it sounds like it's team work with a physician who you trust.

Dr. Lambert:

That is the bedrock of all the, you know, all the therapeutic relationship, but certainly in these difficult to control symptoms which you mentioned it is absolutely critical, yes.

Andrew Schorr:

Okay, thank you so much, Dr. Jon Lambert.

Dr. Lambert:

You're welcome.

Andrew Schorr:

And for all you do in this field, and may you and your colleagues have the research and the knowledge so that—wouldn't it be great if we could be cured or certainly live ever better?

Dr. Lambert:

Absolutely.

Andrew Schorr:

And thank you for your devotion today.

Dr. Lambert:

You're welcome.

Andrew Schorr:

Andrew Schorr on location in London with Dr. Jon Lambert, an MPN specialist here in London. Remember, knowledge can be the best medicine of all.

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