



Patient Power

Newly Diagnosed With Hodgkin Lymphoma: What Questions Should I Ask My Doctor?

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Beth Probert:

So kind of shifting gears a little bit, what would you say, what questions should patients be asking their doctors?

Dr. Burke:

Yes, so if I had a new—if I were a patient with new Hodgkin lymphoma and I were seeing a doctor I would first of all start with the basics, okay? So what's my diagnosis? What type of Hodgkin lymphoma do I have? What's my stage? What tests do I need to determine that stage? And then once all that is in order, what is my overall treatment plan, okay, and how does it look from start to finish? How many cycles of chemo? Are you going—are we thinking about radiation therapy? Are we going to make that decision somewhere halfway through whether to add radiation therapy or not?

These are all key issues and questions that come up. What side effects should I expect during the treatment? Can I work through this treatment? These are all common questions that come up. And then of course prognosis. I think some people with Hodgkin lymphoma are really more interested in hearing statistics, and what's my cure rate? Other people don't want to go there. They just say, look, give me the treatment, and we'll see what happens. And at least speaking for myself a lot of docs will sort of wait for patients to lead that discussion, because we don't want to provide more information than you want to hear and we don't want to provide less information than you want to hear, so a lot of us will wait for our patients to sort of ask that question. And so I would say that is important for patients to go into the visit being prepared to ask what they want to know about prognosis.

Beth Probert:

I think that's great advice, and you certainly gave us some wonderful examples. So we know this is a very overwhelming disease and could be a little frightening. What resources are available to patients for support?

Dr. Burke:

Yeah, well, I think starting—I can think of several. So, first of all, besides your primary physician, your oncologist and the physicians and other types of providers who are treating you, I can think of a couple other resources. I mean, in our personal practice we have financial counselors who can help with questions about cost because that's obviously a big issue for cancer patients. Our practice also employs social workers to help patients with issues like transportation. Our financial folks help people find grants to help pay for treatments. Psychiatric issues and psychological issues that come up with not only patients but also their caregivers and loved ones at home, so providing support for really the whole team and not just the patient themselves.

And then moving beyond the local office I think examples of other places to get support are Patient Power. I mean Patient Power, this organization here, provides amazing educational resources for patients with many different blood

cancers. And then another one that's near and dear to my heart is the Leukemia and Lymphoma Society. Really provides tremendous resources for patients. And just to give a few examples, they have grants to help patients pay for their medications when they cannot afford them. Leukemia and Lymphoma Society offers online webcasts, educational ones, kind of like what we're doing today, to teach patients about diseases.

And here in my local market in Denver LLS puts on an annual in-person educational conference where they invite speakers and literally hundreds—it's a Saturday once a year where hundreds of patients go just to get education about their disease and meet others with their disease to—that's a really great aspect of that conference. So I can go on and on about LLS and everything they do for patients, so I probably should stop there, but that's another example of resources that are available.

And then last I would just add, online, you know, everyone wants to go Google their disease and learn about it, and I'd just advise some precaution there in making sure that you have a resource that is trusted by your physician. Examples of reliable websites that provide really good patient information about how to treat Hodgkin lymphoma would be American Society of Clinical Oncology, the American Cancer Society. Both of those resources provide patient education. And then there's a good website called UpToDate that provides various information about various cancers. So there are some websites that are really good, really reliable. Those are examples that jump to the top of my mind, and I'm sure I'm leaving some out, but just be careful about what you read out there.

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