

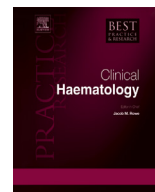


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What your hairy cell leukemia patients want you to know



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A B S T R A C T

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Hairy cell leukemia is different from most other hematologic malignancies because it is so rare. Patient concerns include finding a knowledgeable physician, confirming the diagnosis at the initial presentation, coping with treatment side effects and monitoring for potential relapse of this chronic disease.

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When we were asked to write this article from the patient's perspective, it didn't seem so difficult a project. After all, each of us has lived with hairy cell leukemia ("HCL") for many years. Both of us have had multiple relapses and been treated with several different drugs. We could have just told our personal stories. But this article cannot be written from one patient's point of view. Even between the two of us, our stories are vastly different from each other. Each patient's situation is unique. We have tried to explain our concerns as patients, as well as concerns expressed by other HCL patients we have met as Directors of the Hairy Cell Leukemia Foundation ("Foundation"). We have also reviewed and incorporated questions patients and family members sent to the Ask an Expert feature on the Hairy Cell Leukemia Foundation's website [1].

Orphan disease

Hairy cell leukemia is different from most other hematologic malignancies because it is so rare [2]. Since the incidence of hairy cell leukemia is less than 1 per 100,000 person years [2], most hematologists rarely see an HCL patient. Therefore, physicians need to bring themselves up to date in treating this rare disease. They should be willing to consult with an HCL specialist for an expert opinion. Second

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opinions should be encouraged with any life altering diagnosis, but especially with a disease as rare as HCL. This includes a second pathology review by an expert in HCL. The Hairy Cell Leukemia Foundation's website offers a link to the Centers of Excellence [3] in hairy cell leukemia, which are available for clinicians to contact for advice or referrals.

Referral

Being referred to a hematologist is scary. The patient may have seen multiple doctors for unresolved symptoms or received abnormal test results. They don't understand the results of the blood tests they have taken or the CT scan that shows an enlarged spleen. At this stage, some patients may not know the difference between a platelet and a lymphocyte and not even know where their spleen is located. Hematologists need to understand these new patients are learning a whole new language.

After carefully listening to the patient, the hematologist needs to explain what further tests need to be done to obtain a proper diagnosis. Patients will want to know:

- Why does a bone marrow biopsy need to be done?
- What do I need to do to prepare for it?
- Will I be given anesthesia?
- Based on my symptoms, is a biopsy necessary?
- What are the side effects/risks of a bone marrow biopsy?

Test results must be discussed with the patient as soon as possible. Waiting for test results (especially the results from a bone marrow biopsy) is one of the most anxious times for a patient.

Diagnosis

Be prepared ... once patients have processed the diagnosis, they will ask a lot more questions.

- Are you sure its hairy cell leukemia?
- Is there a cure?
- Am I going to die from hairy cell leukemia?
- What tests were done to confirm the diagnosis?
- Are there additional tests that should be done?
- What do the numbers on my blood test mean?
- What causes hairy cell leukemia?
- Is hairy cell leukemia hereditary?
- How many patients with hairy cell leukemia have you treated?
- Can I speak to the pathologist?
- What are the treatment options?
- What are the short term and long term side effects of treatment?
- Can I continue to work while being treated?
- Can I have children?
- How will I know whether the treatment worked?
- Should I begin treatment now or wait until my blood counts get worse?
- Where should I go for a second opinion?

Patients need to be assured that, while HCL remains an incurable disease [4], there are treatments available resulting in complete remission for most patients and most lead fairly normal lives for nearly normal lifespans [5]. Probably the most important thing a doctor can do to help a patient deal with this diagnosis is to allow time to answer all questions and provide the resources to help the patient navigate this process. This should include a list of organizations that provide support as patients often seek to meet and engage with others sharing their diagnosis [6]. The Hairy Cell Leukemia Foundation's regional patient seminars provide patients with the opportunity to meet others with this rare disease. The Foundation's

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