



Newly Diagnosed With AML? What Patients Need to Know

Tapan M. Kadia, MD

Associate Professor, Department of Leukemia
The University of Texas MD Anderson Cancer Center

Sangmin Lee, MD

Assistant Professor
Weill Cornell Medicine

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

Andrew Schorr:

What's the first thing that family should do, in terms of trying to get enough information?

Dr. Lee:

I think, for AML, what's very important to know is that there are two general behaviors of AML. One is something that needs to be treated right away, as in the same day. Typically, those kinds of patients have a very high white blood cell count, and they're more symptomatic. So, in those cases, I would advocate that you do not have a lot of time to shop around.

So, if you are really far away, you need to do what you can to treat the disease first. Assuming you're pretty stable, if your blood counts are not proliferative and changing, you do have time to ask for an opinion. And I would, like anything else in medicine, I would go to a person who treats a lot of the condition. AML is not a common disease. And treating an AML patient requires not only giving drugs but a lot of supportive care. So, you need to go to someone who sees more AML patients. So, that's what the patient needs to advocate.

So, the first question the patient should probably ask a doctor is how many patients of AML have you treated. And is there someone who you know who has expertise in treating AML? And given the acute nature of things, for us, when patients call, we often squeeze them in same day.

Unlike other kinds of cancers that move slowly, we often see patients on a very short notice because it's an acute leukemia.

Andrew Schorr:

Decisions have to be made fast. So, we've talked a lot about the family role, whether it's somebody your same age, and you're an older person, or the adult child, you can play role the terror, as you referred to, that comes with the

diagnosis. So, it sounds like it's important to sort of pick yourself off the floor, identify a team or consulting healthcare team members who have expertise in the field, to make sense of this IDH and FLT3 and all of the different stuff, and, hopefully, have insurance support, so you can get the testing that's right for you.

Now, with all of these different drugs, if you find that one is not working or no longer working, with this whole array of treatments, is there something else that probably you can switch to, Dr. Kadia?

In other words, you're not out of choices.

Dr. Kadia:

No, you're not. And one of the great things about having these trials and having these new drugs approved is now, we have so much more in our toolbox than we used. Before, like we said earlier, we had two drugs. We had an anthracycline and cytarabine, there's two types of drugs. And we just used those. We combined it with other things. But it was really the same kind of backbone. But now, you have IDH inhibitors. You have FLT3 inhibitors. You have this drug, venetoclax (Venclexta), which has shown remarkable response rates, with a low intensity chemotherapy that's tolerable to people who are 60, 70, 80 years of age.

And so, even if you did not respond, or if you responded and relapsed after your first AML treatment, there's not a significant loss of hope. You say no, there are other things available. There are many drugs in development. There are many clinical trials. And very often, some of the best care you receive is on a clinical trial because you'll have a research team and research nurse, in addition to your doctor, who is constantly monitoring, following every single side effect that you have, trying to address every question you have because it is regulated very closely.

So, there are many options. And, certainly, many of the academic centers and even certain other organizations now are offering these trials.

Dr. Lee:

One thing that is extremely important for patients to realize, actually, for clinical studies, is that each individual patient is not a statistic. So, let's say a drug only has 20 or 30 percent response rate. You don't actually know, a lot of times, if you're going to respond or not until you take the medicine. But if you happen to fall under that 20 or 30 percent that works, it doesn't matter what that success rate is. But you have to make the steps to try. And that's what's the most important thing about treating AML patients.

Please remember the opinions expressed on Patient Power are not necessarily the views of our sponsors, contributors, partners or Patient Power. Our discussions are not a substitute for seeking medical advice or care from your own doctor. That's how you'll get care that's most appropriate for you.

