LEUKEMIA & LYMPHOMA SOCIETY®

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Your Questions Answered About Hodgkin Lymphoma'

Description:

Dr. Hoffman from the Sylvester Comprehensive Cancer Center, University of Miami Health System in Miami, Florida speaks to us about Hodgkin lymphoma and its interesting history. Thankfully, Hodgkin lymphoma is now highly treatable and for the majority of people curable, but not for all. Dr. Hoffman talks to us about what makes Hodgkin lymphoma unique, as well as discusses emerging therapies and long term and late effects for both young adult and older patients diagnosed with Hodgkin lymphoma.

Transcript:

Alicia: Welcome to *The Bloodline with LLS*. I'm Alicia.

Edith: I'm Edith.

Lizette: And I'm Lizette. Thanks so much for joining us today on this episode.

Alicia: Today we will be speaking with Dr. James Hoffman. Dr. Hoffman is an Assistant Professor with Sylvester Comprehensive Cancer Center, University of Miami Health System in Miami, Florida. Welcome, Dr. Hoffman.

James Hoffman, MD: Thank you, great to be here.

Alicia: Awesome, we are so excited to have you and to talk with you today. Today's topic will be Hodgkin's lymphoma, of course. But before we jump into that, we like to know more about our guest speaker. So, what brought you to the field of medicine, specifically hematology/oncology?

Dr. Hoffman: So, again, thank you for having me here. So, in general I was interested in medicine and science kind of early on. I just found, how the body functioned to be kind of fascinating. So, at a young age I was kind of interested in the

sciences. As I advanced through my education, through college, it became clear that I wanted to go to medical school and help take care of patients.

In terms of hem/onc specifically, the minute I got into practice, the minute I started interacting with patients, first as kind of a volunteer and an observer and then a student, it became clear to me that there was something uniquely kind of intense and special about the relationship that oncologists had with their patients. Patients came in, of course, nervous with families that were nervous; and there was an immediate kind of intensity to that relationship that I kind of migrated towards. I enjoyed being a part of difficult family discussions and reacting to kind of nuanced emotional things, and to me it was a natural fit for myself.

And partnering that with the way that the hematology/oncology field is so tethered to science and to scientific advances and to clinical trials, every year there seemed to be better treatments offered, it was a, just a perfect marriage of interest in the patient-care aspects and the scientific aspects.

Alicia: It's always so interesting to hear how a person's interest develops and causes them to move into this field. Again, thank you for all you do for patients and their families.

Dr. Hoffman: It's a privilege.

Alicia: As I mentioned, today's episode will be about Hodgkin lymphoma. And we know that there are two main types of lymphoma, Hodgkin lymphoma and non-Hodgkin lymphoma. For those listening who may not be familiar with lymphoma, can you define what that is for our listeners and how Hodgkin lymphoma specifically develops?

Dr. Hoffman: Yes, so that's a really common question; and it's actually a confusing topic, not just for patients and caregivers, but even for people engaging in medical school and otherwise.

So, lymphomas, in general, the word oma, the suffix oma means tumor or cancer. And the prefix in this case, lymph or lymphocyte refers to white cells. Lymphocytes are white blood cells. So, lymphomas are white blood cell cancers. It's when a white blood cell becomes malignant and starts to overgrow the healthy white blood cells.

White blood cell cancers have come in two general flavors. There's leukemia and then there's lymphoma. Leukemia is when those bad white cells, those cancerous white cells float in the bloodstream; and lymphoma is when they form tumors in the lymph nodes. So, lymphoma is a white blood cell cancer where the white cells that grow, grow in lymph nodes.

Once you have a lymphoma, there's, again, a breakoff into two general categories. There's a lymphoma that is so unique that it gets its own category called Hodgkin lymphoma, and then there's all of the rest of them. They get lumped into a category called non-Hodgkin lymphomas. And non-Hodgkin lymphomas are at least 70 different types. They can range from B-cell to T-cell. They can range from fast-growing cancers that can be cured with strong chemo to slow-growing cancers that may not even need any treatment whatsoever.

So non-Hodgkin lymphoma is really a basket of a diverse group of lymphomas. Hodgkin lymphoma is so unique, like I said, that it gets pulled out of that entire basket. And, in fact, it's interesting to think. All of those other lymphomas are defined by not being Hodgkin lymphoma. They're called non-Hodgkin lymphoma. So it tells you how unique Hodgkin's is, and we can dive into it, if you'd like, about what makes Hodgkin unique; but, again, Hodgkin lymphoma is a white cell cancer where the cells grow in the lymph nodes but has unique characteristics such that it's so different than the entire rest of the basket of lymphomas.

Lizette: Doctor, how is Hodgkin Lymphoma diagnosed? With so many types of lymphoma, is Hodgkin Lymphoma diagnosed differently?

Dr. Hoffman: So, all lymphomas and, in fact, the vast majority of cancers require pathology, require material procured from the patient and looked at under the microscope. And the lymphomas are no different. The diagnosis of every type of lymphoma requires someone to take a biopsy, someone to take the material that was removed from let's say a swollen lymph node and look at it under the microscope. And then the pathologist can identify with special studies what is the cell that has become cancerous? What is the specific white blood cell that has become cancerous?

In the non-Hodgkin lymphomas, we have so many different white cells that fight germs in so many different ways, and any of them can become a cancer. And if this type of cell becomes a cancer, it's this type of non-Hodgkin lymphoma. If that type of cell becomes a cancer, it's that type of non-Hodgkin lymphoma. And Hodgkin lymphoma has some very unique pathologic features. There's a type of cell called a Reed-Sternberg cell which is also sometimes called owl eye cells. It looks like two little owl eyes. And when pathologists see that on a biopsy, they can say this is a lymphoma; and, more specifically, this is a Hodgkin lymphoma. So, all lymphomas, generally speaking, require a biopsy; and it's based on the details of that biopsy that allows us to make a precise diagnosis.

Lizette: And how do doctors, I guess, suspect that somebody has Hodgkin lymphoma? What does the patient present with?

Dr. Hoffman: That's a very important question. So, in general, people with Hodgkin lymphoma have growing lymph nodes. So some people will present to the doctor because they feel a growth, let's say under their armpit or in their neck or in their groin, areas where there are a lot of lymph nodes that can be felt. So that's one way that people know that there's a problem, and then they seek a workup.

Other people, the way the disease evolves in their body, it produces a total body kind of reaction that can involve things like fevers or drenching night sweats or weight loss, sometimes called the B symptoms that we associate with lymphomas. So, people can

present with or without B symptoms, but they present to clinical attention because of swollen lymph nodes or B symptoms. Usually it's one of those two things.

There are some rarer symptoms that can be associated with lymphoma, which we can definitely talk through, but the majority of people, it's growing lymph nodes or it's B symptoms or it's both.

Lizette: And isn't Hodgkin lymphoma associated with a certain age group or age groups?

Dr. Hoffman: Yeah. One of the many ways that Hodgkin's is unique, as we talked about, it's so unique that it's pulled out of the whole category of lymphomas to be special, one of the unique features is the age distribution. Hodgkin lymphoma exists in what we call a bimodal age distribution. There's two peaks to the incidence of Hodgkin lymphoma. But by far and away the largest peak is in this kind of adolescent young adult category, college age students into, you know, early 20s, late teens.

And so that makes it unique because the majority of the non-Hodgkin lymphomas occur much more commonly in older folks. In Hodgkin, the second age peak is, is in the 50s or so. But the most common age at diagnosis is much younger than all the other categories. And this brings with it some very unique challenges, right? You're treating somebody who's 18 or who's 20. There's a, lot of different ramifications to giving chemotherapy than if someone is 60 or 70, things like long-term risks associated with chemotherapy, things like fertility preservation. So, treating Hodgkin in many ways is, again, a unique challenge when compared to many of the other forms of lymphoma.

Alicia: Those are really great points. Doctor, in addition to age, are there any other risk factors that may increase a person's likelihood of developing Hodgkin lymphoma?

Dr. Hoffman: So not really. There's a very, very subtle, potential hereditary component; but the majority of cases, really, are not hereditary in any way, so it's not

based on family history. There are some occupational exposures that can increase the risk of lymphomas in general, certain types of chemical exposures, military chemical exposures. But, again, a lot of those exist more in the non-Hodgkin arena than in Hodgkin where people can have exposures and then have many, many years to have a problem develop.

In Hodgkin's, in general, it's often a very random event, it's not associated with drinking or smoking or anything like that at all. So, you have a lot of people that have no known risk factors for cancer where this kind of comes out of the blue. And when you meet a new Hodgkin patient who's 18, who's 20, who's 22, many of them have never really been touched by cancer in any sort of way. It's not in their field of vision. You know, 20-year-olds, 18-year-olds have a lot of life concerns; but developing cancer is really not on the radar for many of them. And so, there's a real adjustment period at the time of new diagnosis, particularly because of the age that's afflicted.

Lizette: Sure, sure, definitely. Like you said, there's so many different considerations for somebody who's young with providing treatment than somebody that's older. And I feel like there would be different treatments possibly for someone who has no comorbidities who's younger than somebody who has a lot of different comorbidities and may not be able to take the treatment.

So, can you talk a little bit about the treatments for Hodgkin lymphoma?

Dr. Hoffman: Yeah, absolutely. So, and all those points that you made are very important and they're valid. Hodgkin lymphoma has an interesting history. You know, Hodgkin lymphoma, thankfully in modern times, is highly treatable and for the majority of people, thankfully, curable. Not for all, unfortunately, but for the majority.

It certainly wasn't always that way. You don't have to go back too far in history, pre kind of modern chemotherapy where Hodgkin was uniformly fatal. And so, in the earliest days of treatment, they started to really throw the kitchen sink at this. As you could imagine, you have 18-year-olds who would get this awful illness; and they

wouldn't survive. So aggressive radiation and surgery and strong chemotherapies were the standard of the day, and they started to be able to cure some people with Hodgkin.

And, again, another thing that makes Hodgkin unique is what started to happen was you were curing a lot of people with all of these strong treatments, but then these young people had decades of life to live. And then you were seeing all sorts of secondary problems down the road, other malignancies, heart disease and other problems.

So interestingly enough, one of the major developments in the research in this field over the last decade or two has been on how to achieve the same high cure rates with less toxic treatment. Shorter courses of treatment. Removing drugs that start to cause problems.

And there have been other advances which we can talk about with new medicines, but one of the really important fields of progress here has been how do you get really good results with less and with an eye towards long-term wellness, not just being cancer-free?

Lizette: Right. Yeah, I know that there's been some recent advances in the field to remove the more toxic drug. Usually, you know, for years people have said that ABVD was kind of the standard of care; and there's a couple of more chemotherapy regimens for Hodgkin lymphoma. But at this point, isn't it different the way that doctors are thinking about treating somebody when they're first diagnosed?

Dr. Hoffman: Yeah. So, we can dive right in. So, you mentioned ABVD, and ABVD, each letter stands for a different chemo drug; and those are, you know, all old chemotherapy drugs. Thankfully, ABVD for most people is very well-tolerated. You know, people, the era of time where people would throw up from these medicines, thankfully is mostly behind us. And, there can be important side effects; and we can

talk through them, but ABVD works well for most people, and I would say is still the standard of care for the vast majority of newly diagnosed Hodgkin patients.

Some of them get shorter courses of ABVD, fewer doses of ABVD than they used to. Using things like PET-CT scans early on to show that the cancerous cells no longer are viable or alive and being able to kind of shorten up courses of treatment, that has resulted in much less toxicity.

You referenced that there are some new drugs. One of the drugs that's important is a drug called brentuximab, and brentuximab is a really cool medication where it's an antibody that's designed to land on the Hodgkin's cell; and on the tail of that antibody, there's a tiny chemotherapy molecule. And so using that drug for people who had failed ABVD was very valuable.

And then they did a large trial comparing the ABVD and the standard way. And then the other arm of the trial, they removed the B of ABVD which is a drug called bleomycin which has some clear toxicities, including to the lungs, and replacing it with brentuximab. And suffice it to say, I wouldn't say there was a clear winner in that trial but using brentuximab in the place of bleomycin at least has become an option for some patients.

And so, again, this is a way of kind of slowly and steadily advancing the field. How do we give less chemotherapy? How do we maybe use more targeted therapies? Other drugs have been developed for people that relapse after their first attempt at treatment, including drugs that are not even really chemicals to kill the cancer itself, but rather drugs that unleash our own immune systems to fight the cancer. And, the world of immunotherapy, using immune system treatments in lymphomas is certainly in the here and now; and it offers an ability to treat the cancer in a very different way and potentially less toxic or at least with a different side effect profile.

Lizette: Sure, I know that we had a lot of, and particularly young adults that were always asking, because they might not have been able to take the bleomycin, and this

is probably before they could replace it with the brentuximab. But they were asking if, you know, really ABVD, could just be AVD and, and work on its own because they had to stop the bleomycin.

Dr. Hoffman: Yeah, that's a very common scenario. Of all the drugs, that's the one that has to be stopped most. So, what I can tell you is that up front, the ABVD is given. If someone can't take the bleomycin because they have some preexisting lung disease, for example, it's a different story. And maybe they get brentuximab, and there's some other kind of sister regimens that could be used.

But what we have learned is, when you start with ABVD and you get through a couple of courses, and then you have to stop the bleomycin because of toxicity, that the outcomes for those patients are really no worse when you kind of look retrospectively at those. So, it's at least given us the confidence that for those people that we have to, or for those patients that have to stop bleomycin, that they don't have a worse prognosis which is important.

Lizette: Um-hmm.

Dr. Hoffman: And, again, what I mentioned or hinted at earlier is using PET scans earlier, we can often, especially for early stage and favorable risk factor patients, truncate the therapy. So instead of getting, you know, six full months of therapy, maybe they can get four or even two sometimes short courses of chemo followed by a directed do-dose of energy beams called radiation therapy can be used.

So, doctors and patients have a lot of options to talk through, and treatments can really be individualized to the patient's comorbidities and individualized to the patient's tolerance.

Lizette: Sure. Now you just mentioned radiation. I know that radiation was used more so in the past. Is it still being utilized now?

Dr. Hoffman: Yeah. So, radiation for your listeners that might not know, is when you focus kind of an energy beam in a directed area to kill cancerous cells; and it's a highly effective treatment. In the olden days of Hodgkin, people would get very aggressive, almost total body or large portions of their body radiation; and that caused a lot of risk for long-term complications, including secondary cancers.

In modern day, we use radiation more judiciously. We use it in very narrowly defined areas and only in certain circumstances. Sometimes patients with early stage disease, they can get limited chemo and a dose of radiation. People that have very bulky disease, meaning a very, very large tumor at the start, sometimes need a little radiation at the end to eliminate any cancer that might exist in the center of that large tumor.

So, we use radiation but more judiciously. We're careful where we radiate. For example, if you have a 20-year-old female patient who has a mediastinal or a chest lymphoma, we do try to avoid radiation there, because if you have to radiate the chest in a young woman, in a premenopausal woman, you have to radiate some breast tissue; and the risk of breast cancer goes much higher.

So, these are a lot of the considerations. You know, we talk in generalities when we have these discussions, but every individual patient needs to sit down with their own doctor and talk through what is particular about them, what makes them unique. And this way there are many different approaches to achieve a good result; and we try to choose the approach for each patient that minimizes toxicity and maximizes efficacy.

Lizette: Sure. And is the treatment different for folks that are older and have more comorbidities?

Dr. Hoffman: Yes, it can be. Older patients with Hodgkin, older age is one of the adverse risk factors. So, patients that have higher-risk Hodgkin sometimes, well certainly can have a higher risk of recurrence, and sometimes even are considered for

stronger treatments than ABVD. Young people can be, too, if they have a lot of adverse risk factors.

But as a general approach for the purposes again of generalizing across broad numbers, we use ABVD in 20-year-olds. We use ABVD in 50-year-olds. If you have a 60-year-old with Hodgkin's, a heavy smoker and has early COPD, that's going to be a patient for whom bleomycin may be particularly dangerous and probably we would attempt to avoid it.

Edith: Lizette, you mentioned comorbidity. What does that term mean?

Lizette: Thanks, Edith for asking that question. Let me clarify, comorbidity means having another condition along with your diagnosis, so if you have Hodgkin lymphoma and you have other medical issues that you're also dealing with.

Now, bleomycin has a lot of lung toxicity. In this COVID-19 era, were patients that have taken bleomycin or that were on bleomycin, were they more concerned or were you as a doctor more concerned about the lung toxicity in case of COVID?

Dr. Hoffman: Yes. So, when I think about it on a patient-by-patient basis, you know, most of the people that have already had their bleomycin and may have some lung issues, obviously, those decisions were made before, before COVID. Anybody who has had bleomycin and develops some chronic lung issues gets put into a category of chronic lung disease, things like COVID or even things like influenza and other things are certainly higher risk.

I can see in the modern times where COVID is a huge concern for everybody, people may be saying, "Well, let's not use bleomycin now because if you have an acute lung toxicity, you know, in the setting of COVID being so rampant, it could be particularly dangerous" and perhaps some might decide to use brentuximab in its place, particularly for that reason.

A lot of the bleomycin issues take time to develop and can even be more chronic in nature, but some can be more acute. So I would say at the very least, we, we'll evaluate patients very, very carefully based on preexisting lung issues, smoking history, etc. before using bleo because, again, we know COVID is going to be amongst us at least for many more months.

Lizette: Right. And, just for the folks listening, bleomycin is still utilized; and it still has activity.

Dr. Hoffman: It's still an important drug that's used in the majority of Hodgkin patients. The B of ABVD is still bleo. And what your doctors are going to do, and what they should definitely talk you through, is consideration of pretreatment lung testing, make sure the lungs are good before, and careful attention to symptoms. So, if a patient on ABVD has a dry, annoying cough, that's something that we evaluate more carefully than if somebody on the street mentions they have a dry, annoying cough.

Certainly, things like shortness of breath are evaluated very carefully before we give another dose of bleo. I think it's important for your listeners to have a healthy concern for all chemotherapy drugs and to be alerted to potential side effects of all chemotherapy drugs. But I don't want to advertise that bleomycin is this horribly dangerous drug that should be avoided at all costs. It's an effective, helpful drug. It just needs to, like all of our medicines, it needs to be used with careful attention and good communication between a patient and their doctor.

Lizette: Sure, definitely. Well said. And are there any new therapies? I know that you mentioned immunotherapy. I know that brentuximab is one of the newer therapies. But is anything else utilized with Hodgkin lymphoma, even transplants, or in the future, CAR T-cell therapy?

Dr. Hoffman: Yes. So, there are a couple of good things that we can touch on. So, firstly, yes, we definitely use stem cell transplant. The type that's used is called autologous stem cell transplant where we basically use our body's own stem cells to

recover after high doses of chemotherapy. That is still a very effective way to cure people with Hodgkin that have a relapse. So it's still very much a part of a standard-of-care approach; and it's a safe and effective thing to do.

These, what are called checkpoint inhibitors where we remove the brakes on the immune system, I hinted at it earlier, a medicine called nivolumab, for example, can be very, very helpful for patients that have relapsed Hodgkin, basically allows the immune system to kind of wake up against the cancer.

I can give you a brief story. One of the most dramatic patient encounters I've ever had happened many years ago now. I had a patient who was almost exactly my age, and immediately I bonded with her, a very sociable, wonderful person. And we treated her initially with, and we, you know, we talked up the good prognosis of Hodgkin and we talked through all this stuff that we've been talking through here. And she was one of these very, very unique cases. And she was actually treated with AVD and brentuximab on clinical trial. She was actually randomized to that arm of a clinical trial.

And very rare and it's shocking to me, her disease really kind of grew right through that treatment, which is very, very rare to have disease that's refractory to initial therapy in Hodgkin. And she went from a very well person to a very ill person in very short order, almost to the point where we were even having some discussions that she was bringing up and her mother about hospice.

And then around that time the drug nivolumab, which had been used in other cancers, was being tested in Hodgkin in several centers. I reached out to a colleague to get a little bit more information, and long story short, her insurance allowed me to treat her off label with nivolumab; and within two weeks, the disease was almost gone, and she went into remission. And she's alive and well years, years later. And it always just struck me how there's an example of how a medical advance can happen in real time and take a person who was a young, healthy, vibrant person and who had an awful

problem that was going to shorten her life for sure, and now was in remission and probably cured. So that drug, nivolumab, was another kind of really critical drug for relapsed Hodgkin; that whole class has been. So, again, it's brentuximab, it's the nivolumab and its class of medicine.

And then the final thing, as you mentioned, CAR T therapy. CAR T therapy is a really exciting approach where we basically manipulate the immune system to fight cancer. And there's drugs in that family that have been approved for leukemias and lymphomas, not yet for Hodgkin, but there are approaches on clinical trials that are exciting in that regard.

So, the future is still brighter with new drugs to come, but we have so much more to work with now than we did years ago.

Alicia: That's an awesome story. That's great to hear.

Lizette: Yeah, it is. Wow.

Dr. Hoffman: Yeah, she's a real miracle, and it couldn't have happened to a more wonderful person. So, you know in our field as oncologists, we, unfortunately, deal with a lot of sad stories, but we deal with a lot of really amazing stories; and we need that, right? It can be very heavy otherwise. And she again, exemplified a lot to me about how and why we need to keep pushing for advances because they have very tangible results on, on people.

Alicia: Absolutely. Doctor, here at LLS we encourage patients to speak to their doctors about clinical trials since it's a topic that many tend to shy away from due to thoughts about clinical trials possibly including placebos or sugar pills or someone being tested as a guinea pig. Can you spend some time speaking about the importance of clinical trials?

Dr. Hoffman: So, I appreciate the chance to speak on that because this is a very, very important topic; and awareness needs to be increased. People can have this view

that they kind of don't want to be a guinea pig so to speak. So, we need to talk people through it.

There are many types of clinical trials. There are clinical trials where something worked in mice and really smart scientists think it might work in people, but we have no idea even how to dose it; and so we give a little bit to different people; and we make sure there's no side effects.

And that process advances all the way until what we call Phase III clinical trials where the drug has been tested, we know its side effects, we know its dosing, and we're now testing it on top of standard therapy to see if it performs better. No one does clinical trials where anybody gets less than the standard of care. So you never have to worry if you're putting yourself on a clinical trial that you're not getting appropriate care. There's a lot of safeguards to make sure that could never, ever happen.

So clinical trials, for example, if someone was going to offer a patient a clinical trial where they were to get ABVD plus placebo or ABVD plus brentuximab or plus a new experimental medication, everybody on both sides will have to get ABVD because it's unethical to give somebody less than the standard of care.

So for anybody listening, if a clinical trial is proposed to you, my strong advice would be not to just turn it away because it's quote/unquote "experimental" but to listen to, carefully to what the options are. If your doctor is recommending to you a treatment and is offering a clinical trial where you'll either get the same treatment that he or she is recommending, or that treatment plus a new medication. That's not to say there's no risks on being on a clinical trial like that, but you have to understand that's a lot different than you're going to get the good medicine or you're not going to get the good medicine.

And it's by these clinical trials that we can prove these advances and then we could keep pushing the field forward, so no one should subject themselves to risk just to maybe push the field forward. But if you think and you talk through these trials

carefully with your doctors, you will see that nobody on either side of the trial is going to get less than what's appropriate. And I think that's important for people to understand.

Alicia: Well said, thank you.

Edith: Dr. Hoffman, you mentioned some side effects. What are some other long-term and late effects of treatment for Hodgkin lymphoma?

Dr. Hoffman: Yeah, so we've touched on some but to get into them in more detail. So, one of the risks with many chemotherapy drugs is secondary cancers. And people that are treated with chemotherapy drugs are at slightly increased risk of secondary cancers and need very careful and appropriate screening. So whatever age-appropriate screening is, colonoscopies, mammograms, Pap smears, those types of things, dermatologic evaluations for skin cancers, so it's not a major risk in terms of life-threatening risk, but it is an important consideration for people that have been through chemotherapies like ABVD.

Risks related to heart disease, people that have been through ABVD, it's almost like a risk factor for developing cardiovascular disease, not to the same degree, but like smoking or being overweight or having diabetes. So it's something that's put into consideration in terms of making sure that people's cholesterol's good, people are exercising, people have good blood pressure control.

We talked about the B medicine, bleomycin, with the risk of lung toxicity. But if it's given carefully, monitored carefully, that risk tends to be low. The drug Adriamycin causes cardiac issues in a minority of patients, which is why people get echocardiograms first and are monitored carefully.

Thankfully, all of the risks that I'm mentioning are small. But, again, for people that are 20 years old, have decades of life in front of them, long-term risks need to be very

carefully considered. And, again, it's why we do everything we can to give only the amount of treatment that's needed and not more.

Edith: Some patients feel a bit hesitant when talking to their healthcare team. How important is it for patients to have an open communication with their healthcare team?

Dr. Hoffman: Well, I think one thing that's wonderful, and a lot of this comes through organizations like the LLS, is that people and caregivers have forums like this where they can hear and educate themselves. They have forums where they can meet people that are going through this just like them or have been through it. And I think that those offer excellent ways for people to get reassurances and have their questions answered.

With all of that said, I think the relationship between the patient and their doctor and the patients' caregivers and their doctor and the team surrounding the doctor is critically important. Patients need to know that there are no bad questions, that it's okay to repeat questions, it's okay to ask for clarity. Patients shouldn't feel rushed. They should never feel dismissed. They should never feel that their medical team feels threatened by getting asked good, hard questions. These are things that each of your healthcare providers would ask if when related to their own medical care or those of their loved ones.

And, sometimes patients get nervous when they have to choose their doctor, choose their medical team; how do I know that this doctor or this medical team is great and that they're going to do a great job? It's hard for people to evaluate how knowledgeable a doctor is. You can look at credentials, of course, but I think one thing that we can all do is when you meet your healthcare team is make sure that you feel comfortable that your needs are going to be met, that your questions are going to be answered, that they're going to be answered promptly, and that support is going to be given as you go through the months of treatment.

Being an oncologist, being an oncology nurse, oncology pharmacist, this goes well beyond dosing chemotherapy. There's a lot of support, there's a lot of education that has to go into taking care of patients, and I think that every patient needs to demand that from their medical team and they need to look to find it if they don't find it immediately.

Lizette: Yeah, definitely people tend to contact us here cause we have information specialists that can speak to patients and caregivers about their diagnosis and their treatments, but a lot of the questions we get are those quality of life issues.

Dr. Hoffman: Well, I can give you some advice. It is true that the patient encounters in modern medicine can feel a little bit rushed and time can sometimes be tight and doctors can be running behind, and all of those things, but I think what's important you can always ask your medical team, "What's the best way to reach out with questions that are maybe not time urgent?" You know, of course, if the question is, "I'm having a fever, what do I do?" you have to be able to get that addressed immediately and time doesn't matter.

But if you have more kind of broad questions about long-term toxicities, about supplements that you've read about or different things, what I think is fair to do is say, "Hey, hey, doc; hey, nurse, what is the best way for me to communicate with you that you could answer at your convenience?" And whether that's email or whether that's messaging through an electronic medical record, I definitely let it be known to my patients that I'm there to answer those types of questions.

I think that patients that come with their question's kind of ready to a visit those visits can definitely be more efficient, and I always encourage that. I say, "Write down your questions so that when you come you don't feel anxious that you're going to forget to ask them." But I do think that patients need access to their medical team at off hours and outside visits and I appreciate when patients reach out in those ways cause then, when I have time, I sit down and I answer all of those questions. So, I think that

some sort of agreement can be made about how we communicate and when we communicate that balances sometimes the timing of a single visit with the needs that patients have to have their questions answered and their anxieties addressed.

Edith: Thank you. What are common questions you hear from patients and their families when told they have Hodgkin lymphoma?

Dr. Hoffman: So, you know, I think at the time of initial diagnosis it seems very surreal to patients. Like I said, you know, these are college students with all sorts of aspirations and you're talking to them about cancer and chemotherapy and scheduling and what do I do with work and school. I think, in the beginning, it can be kind of overwhelming, and so things go slow and are repetitive. I think once people get their bearings, the type of questions that we get asked are, of course, my prognosis, the treatment plan, the schedule, alternatives to treatment, long-term issues that you've mentioned, fertility is a common question. Many people have a lot of questions on natural approaches to treating cancers, alternative medicine, alternative to conventional Western medicine so to speak. So, all of these things are, are commonly brought up. Questions like, "Should I get a second opinion?" I think that's a very good question to ask. I think second opinions can be helpful for sure.

So, again they're typically the here and now questions, "What's it going to be like on chemotherapy? What's my life going to look like? How am I going to feel?" And then it's the more kind of long-term big picture questions like, you know, "Am I going to be okay?" and everything in between. So, interestingly enough, some patients focus very narrowly on the here and now and others dismiss almost all of that and just kind of want to know the long-term ramifications.

As a practitioner, I try to play off of the patient and their family so that I'm not delivering messaging that's important to me outside of certain essential things that need to be said, but really committing to use our time efficiently to address what it is that's on the patient's mind and what's their concern.

Alicia: Such great feedback. Dr. Hoffman, is there any other information that we didn't discuss that you think our listeners would find important and necessary to just discuss with their healthcare team or maybe just within their own families?

Dr. Hoffman: Yeah, I think that there are many ways to deal with the stress of going through something like this, but I think that patients and their families should take full advantage of groups like the LLS, of certain web forums, of certain video blogs that now exist. I think that patients will often learn more from seeing their peers that have gone through this, from having advisors even outside of the medical team, and they start to feel like this is something that they can do and when they see that and when they hear that from outside of the clinic, I think it's really, really helpful.

My strong encouragement is for patients to empower themselves to learn and read to the extent that they're comfortable. It's okay to rely on family and friends. It's okay to talk about it amongst a narrow group or a more wide group or even advertise it on social media, find the ways and help you breathe through it, help you sleep at night, put one foot in front of the other, and you'll see that you'll get into your rearview mirror like many of your peers have already done.

Alicia: Such great advice, and we couldn't agree more. We always encourage our listeners. And you know, that's really why this podcast was formed to allow people to see that a conversation can happen, that, you know, questions are normal, questions can be asked of their healthcare team, their physician, their nurse, their, even their family members. So, we couldn't agree more with the whole idea of, you know, stay encouraged and, and empower yourself when it comes to such a challenging time such as a cancer diagnosis.

Dr. Hoffman: Yeah. And I'll say, I would say one final piece that I get asked a lot these days is, you know, because of COVID, a lot of people have concerns like, "How am I going to get through treatment of cancer when I'm so worried about being at my doctor and being near a hospital?" It's almost like everyone is so COVID obsessed that

our cancer patients almost feel, you know, they can't get the attention that they need. And I can tell you that every medical center, every cancer center is working very hard to keep patients safe through this time, to put precautions in place so that people can get the treatments that they need. And everyone out there should feel comfortable that if they feel something wrong, that they get care, that they get treated and not be so fearful of COVID that they don't take care of themselves in other ways cause we've seen a little bit of that in our own practice.

Alicia: Absolutely. That's definitely comforting advice cause we also get the same questions regarding, you know, just being a patient and may, whether it be newly diagnosed or, you know, further along the way, but how it relates to COVID, so that's definitely comforting to hear.

Dr. Hoffman, this has been such an informative conversation and you provided such great advice for patients. Thank you for making the time to chat with us today and especially what you do for patients and their families and the care that you provide. Thank you so much.

Dr. Hoffman: Thank you guys; I've enjoyed it.

Alicia: Awesome. And for those who would like more information about Hodgkin lymphoma, please visit www.lls.org/lymphoma. Thanks so much for listening.