

TRANSCRIPT



Communicating with your Healthcare Team

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Slide 1 - Communicating with your Healthcare Team

Lizette Figueroa-Rivera:

Hello, everyone. On behalf of The Leukemia & Lymphoma Society a warm welcome to all of you. We have over 900 people participating from across the United States and several countries around the world, including Australia, Canada, Germany, France, Great Britain, India, Mexico, Sweden and South Africa.

Special thanks to Mrs. Alison Mayer Sachs for sharing her time and expertise with us today.

Before we begin, I'd like to introduce The Leukemia & Lymphoma Society's Executive Director of Education & Integration, Karen DeMairo, who will share a few words. Karen, please go ahead.

Karen DeMairo:

Thank you, Lizette. I would like to add my welcome to the patients, caregivers and healthcare professionals attending the program today. The Leukemia & Lymphoma Society exists to find cures and ensure access to treatment for blood cancer patients. Our vision is a world without blood cancer. For more than 60 years LLS has helped pioneer innovation, such as targeted therapies and immunotherapies that have improved survival rates and quality of life for many blood cancer patients. Through the efforts of our dedicated volunteers and supporters we've been able to invest over \$1 billion in research to advance therapies and save lives. Until there is a cure, LLS will continue to fund promising research from bench to bedside.

LLS also recognizes that effective doctor-patient communication is an essential clinical function in building a therapeutic doctor-patient relationship, which is the heart and art of medicine. And we're fortunate to have as our presenter today Alison Mayer Sachs, a certified oncology social worker and immediate past President of the Association of Oncology of Social Work, or as we commonly say, AOSW. AOSW is dedicated to the enhancement of psychosocial services to people with cancer, their families and caregivers. We appreciate her dedication to supporting our mission and her commitment to patients living with all types of cancers. I'd like to thank her for providing us today with important information on the

importance of patient-provider communication. Thank you all. Enjoy our program. And now I'll turn the program back to Lizette.

Lizette Figueroa-Rivera:

Thank you, Karen. And we would like to acknowledge and thank Genentech & Biogen, Bristol-Myers Squibb and Takeda Oncology for support of this program.

Lizette Figueroa-Rivera:

I am now pleased to introduce Alison Mayer Sachs, MSW, CSW, OSW-C, Director of Community Outreach and Cancer Support Services at Eisenhower Lucy Curci Cancer Center at Eisenhower Medical Center in Rancho Mirage, California. On behalf of The Leukemia & Lymphoma Society, thank you for volunteering your time and expertise with us. Ms. Sachs, I'm now privileged to turn the program over to you.



Communicating with your Healthcare Team

Alison Mayer Sachs, MSW,CSW, OSW-C
Director Community Outreach &
Cancer Support Services
Eisenhower Lucy Curci Cancer Center

Slide 2- Communicating with your Healthcare Team

Alison Mayer Sachs:

Well thank you very much, Lizette and Karen for that lovely introduction. And thank you all for joining us today. For me in California it's for joining us this morning. For the rest of you it's all different times of the day. I think it's very telling that we have over 900 people on a call about communication and how you speak with your healthcare team. That tells me how important this is to all of you and how important it is to those of us who are at the other end, and part of a healthcare team.

In today's healthcare world it is complicated, and it can be confusing. And being able to communicate and communicate well is often the answer to getting the best care possible. So I'm delighted to share some tips, thoughts and ideas with you all, and I hope you benefit from it. So let's get started.

How Much Do We Really Want To Know?



Slide 3- How Much Do We Really Want To Know?

When we talk about communicating with our healthcare team we want to talk about, first and foremost, how much do you really want to know? It's important to take a step back for a minute, know yourself, understand what it is that you need to know so you can feel more comfortable and you can be an informed patient.

Communication

No matter how good a practitioner your doctor may be, if you don't understand what he tells you, or if he doesn't listen or clearly answer your questions, your care will not be the best it can be.

Knowledgeable, active patients are more likely to do well and less likely to get severely depressed than passive ones. They can become active participants in their care and active partners with their physicians, rather than remaining passive consumers.

Harold Glucksburg, MD. *Cancer Care, A Personal Guide*



Slide 4- Communication

When we talk about communication we also talk about two ways. It goes both ways. It's communicating from you to your healthcare team. It's your healthcare team communicating back to you. And the truth is no matter how good your doctor is, or your nurse, or your social worker, or any member of your healthcare team is, if you don't understand what they're saying, or if they're not listening clearly to you, your care is just not going to be the best it can be. When you look at the little drawing in the bottom of the slide - see that we have effective communication right smack in the middle of a whole lot of other arrows. And we talk about respect, we talk about being calm and focused, we talk about communicating often with frequency, and we talk about how we engage folks in effective communication. We know that active, participatory patients are more likely to do well and, studies have shown, less likely to suffer depression or other concerns and issues from a mental health perspective. The more active you become in your care, the more active you are with your physicians rather than being passive, we know for a fact, the better care you're going to get.

Effective Patient-Doctor Communications

A patient who is a good communicator:

- Will be mindful of the doctor's limited time.
- Will be concise in her communication.
- Will ask the meaning of words and concepts she does not understand.
- If interrupted, will ask the doctor to stop and listen to her.



Effective Patient-Doctor Communications www.about.com Trish Toney, 11/2007

Slide 5- Effective Patient-Doctor Communications

But the thing is, what's communication look like? What does it mean? When we talk about being a patient communicator we talk about how you're mindful of time, how you're concise, what meanings of words mean and what you do when you're interrupted. You know, if you look at the little cartoon in the bottom--I'm not sure that you can read it clearly--but it basically is the doctor sitting there talking to the patient and saying when I said you could tell me anything I didn't mean you could tell me that I'm losing my hair. It's not what you say; it's how you say it. And being mindful of doctors' time is the first and foremost thing we have to come to grips with in today's modern world of medicine. We have to prepare ahead of time. Know that the visit is probably going to be shorter than you expected. And you need to write your questions down. And writing questions down is a theme we're going to visit again, again, and again throughout this presentation. You need to be concise. What do we mean by concise in communicating? I like to say almost speak in bullet points. When your questions are prepared ahead of time, stick to the facts. So in other words, when someone goes in and says Doctor, I was speaking to my daughter the other day, and she explained to me that her best friend's mother who lives down in Florida has the same kind of diagnosis as me, and she was telling her daughter--now, too much information. Be concise. Speak in bullet points. The same thing can be said, which is, you know, I heard that someone is

going through what I'm going through, and this is what their doctor shared with them. Would that work for me?

When you don't know the meanings of words and concepts, ask, ask. You know, I often say doctors speak medecalese. Well, stop your doctor. Ask for a definition or a description when they say something you don't understand. Getting diagnosed with cancer is like being dropped in a foreign country. You don't speak the language, and no one gave you a map. You are not expected to understand all of these foreign phrases, what they mean, where they come from. Your team has gone to school for years for this. You need to ask them, what did you mean by that?

And lastly, if you're being interrupted, stop. Stop the doctor. Stop and ask them would they just listen for a minute. There was a study done quite a while back that said on average--listen to this--physician's wait about 18 seconds--that's 18 seconds--before interrupting patients' narratives of their symptoms. That's a study back in 2015. So if your doctor interrupts you, and based on that study we can just assume he or she probably will--politely, politely, ask them to listen to your entire list of symptoms or let you finish your question first. It will make a difference.

Effective Patient-Doctor Communications (continued)

A doctor or practitioner who is a good communicator:

- Has respect for her patient.
- Has the ability to share information in terms her patients can understand .
- Doesn't interrupt or stereotype her patients.
- Has the ability to effectively manage patients' expectations.

Effective Patient-Doctor Communications www.about.com, Tish Torrey, 11/2007

Slide 6- Effective Patient-Doctor Communications (continued)

When I said communication goes two ways, that's exactly what I mean. Just a little bit ago I gave you some bullet points about how you can be a good communicator as the patient, but you also could know how does your doctor or practitioner do as a good communicator? They need to be respectful of the patients they work with. You know, good providers, good doctors and nurses, clinicians, understand that a sick or injured patient is highly vulnerable, and being respectful goes a long way towards stepping back, listening, and that allows the patient, us, to explain our symptoms. It also allows us to take responsibility for decision-making and to follow instructions clearly. So it's important that your doctor or practitioner has respect for you.

They also need to have the ability to share information in terms we understand. That's that med-speak or medecalese I was talking about before. It's okay for them to speak in those terms. As a matter of fact, if

they do and you ask them to explain, then you're engaging in dialogue and learning from them. You are also learning the appropriate terms to use as you move forward through your treatment. That will help you be a better communicator and will speed up communication. In other words, you're using the same language together.

A good provider doesn't interrupt and doesn't stereotype. Listen, we all know it's easy for us to interrupt when we're in a hurry or when we have a short amount of time. But a good practitioner and a good communicator knows that if we don't get it right the first time we're just going to have to do it over with you, have that conversation all over again. So listening, slowing down, it makes that provider help you get better outcomes.

And lastly on that two-way communication, a good provider is able to manage your expectations as the patient. By helping patients understand what are the next steps, what are the possible outcomes and what's the end results, what are the ramifications of those outcomes, that will help us in the long term better understand what our treatment is, what our problem is and to move forward through it clearly.

COMMUNICATION

- Good communication between patients, family caregivers, and the health care team is very important in cancer care.
- Patients with cancer have special communication needs.
- Some patients and families want a lot of information and choose to make decisions about care. Other do not.

Slide 7- Communication

You know, when we talk about communication, and perhaps I should have started with this slide. It's a definitive slide, a definition, but good communication between patients, their loved ones, caregivers and the healthcare team is vitally, vitally important in cancer care. You know, the goals of good communication are to build the trusting relationship, to help share information throughout for each other and to help the patient's family be able to talk about feelings and concerns and be clear and helpful in doing so.

You know, patients with cancer have special communication needs. We know when someone is diagnosed with cancer it can be a life-threatening illness, and even though treatments and advances have brought us to the point of cure and remission with many patients, someone who hears they have cancer often will feel the anxiety about treatments that are difficult, expensive and complicated. Decisions about care can be very hard to make. And good communication can help us together improve what our quality of life will be, make the best decision.

When patients and doctors communicate well together, we see more positive results. Patients are usually more satisfied with the care and feel more in control. We're more likely to follow through with treatment, certainly more informed and, by the way, more likely to participate in a clinical trial, which is hugely important. It is very rare for someone to be diagnosed with diabetes, for instance. They don't go diabetes-death. Or if they have a heart problem they don't go oh, gosh, I have atrial fibrillation-death. But when people hear cancer, often, often they will go cancer-death right away. This doesn't happen with other diagnoses, and we do have very special communication needs as cancer patients and as beloved ones and family of cancer patients. Communication and how we do it is vital.

And then we have to remember in that last bullet point that some patients and families want a lot of information and want to make decisions about their care, while others do not. I think it's really, really important for you to let the healthcare team know how much information you want. What can you handle? How much anxiety does information provoke? You know the last thing we want is someone walking out of an office, or sitting at the end of an office a puddle on the floor because they couldn't, couldn't hear everything that was given to them, or it was so anxiety-provoking. Other families possibly to, to personal religious beliefs, to ethnic backgrounds, may choose a point person in the family they want to be their main communicator. That's important, as well, and we need to know that, and we need to talk about it.

The need for information changes as we move through cancer treatment. It needs to be flowing. We need to be talking about at all times who is speaking for you? Do you speak for yourself? How much information do you want to know? Many times physicians have told me, you know, I take my cues from the patient. I see how much information they want, and then I know how much information to give them. Well, if that's the case and that's your doctor, you need to tell them. How much information do you want to know?

COMMUNICATION

- Communication is important at different points during cancer care
- End-of life discussions with the health care team may lead to fewer procedures and better quality of life.

Slide 8- Communication

We talked about communication is very different at different points throughout cancer care and treatment. Communication is different up front when you're first hearing about your diagnosis. You need to make treatment choices and decisions. You need to make changes in lifestyle, perhaps, whereas throughout treatment you might have different questions. While you're in the middle of treatment, how to cope with

side effects, what's next? And lastly, at the end of treatment, what are the goals there? One time and most often the elephant in the room might be end-of-life discussion. What do we need to talk about? You know these discussions are so much better early on when you have the time to think about things? It may never happen. You may never need to have it, but it's good to know. Let your team know what you want to know. It's often a discussion about quality versus quantity.

Taking Control of Your Medical Care

- Be a "self advocate"
- What are you looking for in a provider?
- Don't make hasty treatment decisions.
- When seeing a new physician, surgeon, or specialist, ask the scheduler how long you'll have with the doctor.

Guthrie, Catherine. How to Train Your Doctor. www.oprah.com

Slide 9- Taking Control of Your Medical Care

When we talk about communicating it's really about taking control of your care, about how to be a self-advocate, how to take an active role in your cancer care. And you know, this can be a very positive experience. When someone says well there's nothing positive about cancer, well, I don't know about that. There can be. It's how you reframe something, how you rethink about it. When you take an active role it can be a positive experience because it can give you a sense of control certainly in a time of uncertainty. You know this doesn't have to be this time-consuming, on the internet, reading constantly practice. It doesn't have to be that difficult. It can be as simple as asking a few more questions when you visit with the doctor. And later we're going to share with you questions to ask at time of diagnosis, during treatment and after treatment that we think you'll find very, very helpful.

We don't want you making hasty treatment decisions. This is a matter of control again. The first thing you need to ask always--and I want to reiterate this--the first thing you need to ask your doctor, how long is it medically safe for you to wait before you make a decision about treatment? This way it's how long you can wait before you choose a treatment decision, if it's safe for you to do so. It allows you to get more details about your diagnosis and treatment, to read them at home at your own pace. It's also important to always ask your doctor, have you discussed all my treatment options with me before I make a decision? And that includes, what if I don't choose an active treatment? What if I don't do any treatment, Doc? What does that look like for me?

And then taking control can also look at when you're seeing a new physician, a surgeon, a specialist. Important to find out how much time do you have with that provider? Because the answer to how much

time you have will really help you prepare for your time together, for your appointment. For instance, new patient appointments are usually lengthy, or hopefully lengthy, allowing you plenty of time to ask the doctor on the intricacies of your diagnosis and your treatment options, what you need to know. But if it's a follow-up appointment you might have to be very judicious, think very quickly on your feet, have those questions ready to ask because that's a short 10-, 15-, 20-minute follow-up appointment. All of those four bullet points, again, about taking control of your care. And again, all tied into how you communicate with your healthcare team.

Taking Control of Your Medical Care

- Turn a three-ring binder into your healthcare journal.
- Go to every appointment with a smart friend or family member.



Guthrie, Catherine. How to Train Your Doctor

Slide 10- Taking Control of Your Medical Care

Some other tips for taking control of your medical care, turn a three-ring binder into your healthcare journal. I know many of you have heard this before, but a binder, or a notebook, or a loose-leaf, whatever you want to call it, it's a great place for everything to gather about your healthcare. You can add blank pages for notes and dividers with pockets for test results. You can have physician messages, treatment information in there. Take it with you to every doctor's appointment. You can add things at the time. And you know, if you're admitted to a hospital, give it to a--entrust that binder to a friend or a relative and they bring it with them. So any question about your health history--you know we're in the Palm Springs area in Southern California, so we're a resort community, snowbirds so to speak. I can tell you how often we have patients unexpectedly at their end admitted to our hospital, and there's a whole flurry of how to get information about them. They're in the middle of treatment, or they're newly diagnosed, or they're post-treatment. Having that binder would make a huge difference in ensuring good medical care, and again, it's a way of communicating.

And then you all have heard this time and time again. Bring someone with you. But please look at the slide and notice that I have underlined to every appointment bring with you a smart friend or family member, and that smart is underlined because truthfully no matter how organized we are, most of us just don't remember all the doctor has to say. Most often we hear the first and the last things they say and very little in between. So having someone with us who can help take notes, offer another perspective, and also help you just remember what was said, go through it with you. Sometimes they even might have a question that you didn't think of.

We're hearing today quite often people also suggesting that you record conversations. I'd like to remind everyone that there can be legal implications of hidden recordings of anyone, so always ask permission up front of any provider. Would it be okay with you if I record this discussion? That's very important. Don't just do--no recorders in pockets, please. That's not fair.

Tips to make the most of Your Appointment

- Write down a list of questions and concerns.....prioritize!
- Take notes about what your doctor says, or ask the person with you to do so.
- Learn how to access your medical records, so you can keep track of test results, diagnoses, treatment plans and medications.
- Ask for your doctor's contact information and their preferred method of communication.
- Ask how the office runs.
- Ask who the different members of your health care team are and what they do.



NIH: Talking With Your Doctor

Slide 11- Tips to make the most of Your Appointment

When we talk about communicating together and we talk about the different ways to communicate what your role is, what the doctor's or healthcare team member's role is, there are little tips to remember. And we talked about writing down questions and concerns, but here's the thing. Don't just write them down. Prioritize them before you go into the appointment, maybe the night before, maybe the morning of, because we do know that time is limited, and it's very important to get to those most important questions to you first. I also urge you--often people will say yeah, no problem. I keep pad and pen right by my bed. But if there's other folks you live with, someone else who sleeps in the same bed or same room as you, that means they have to crawl over you to write their questions down. I think it's much easier if you would keep that pad and paper for everyone to write their questions down in a more central location, perhaps the kitchen countertop.

Consider bringing a close friend or family member with you so they take notes, either you take them or the person with you can take the notes. Know how to access your medical records. This is really important, so you can keep track of test results, diagnoses, treatment plans, medications. Place all of those in that binder we spoke about in that previous slide. Ask, how do I get my medical records? Many of us are on what's called EMRs today, electronic medical records. How do you have those? Ask, do we have an electronic medical record? Is there a place for me? Some people use certain things called MyChart. How do I find out? How do I get hold of this information?

Also, ask for your doctor's contact information and their preferred method of communication. Would they like you to text? Do they want you to call the front office? Do you fax? Do they email? How is the best way for you to communicate directly with your physician, with your nurse practitioner, with your front desk, your scheduler and your financial counselor? Are there different ways to communicate with each of those folks? And that's kind of really asking how the office runs. Who's in charge of what, what do they do, how

do you find them? Who are the different members of your healthcare team? I know many places today are placing this information right in your new patient packet, but you know many of us that have been told we have cancer, we get handed that new patient packet, take it home and drop it somewhere. So if you don't know and you're rereading this presentation and look at this slide, see if you have that new patient packet and look through it. You might find most of this, or much of this information has already been given to you. We just didn't hear it the first time.

QUESTIONS TO ASK 

When you're told you have cancer:

1. Exactly what kind of cancer do I have?
2. How do I get a copy of my pathology report?
3. Where is the cancer located?
4. Has the cancer spread beyond where it started?
5. What's the cancer's stage? What does that mean?
6. How does this affect my treatment options and long-term outcome (prognosis)?
7. What are my chances of survival, based on my cancer as you see it?
8. How much experience do you have treating this type of cancer?
9. Will I need other tests before we can decide on treatment?
10. What are my treatment choices?
11. What treatment do you recommend and why?
12. What's the goal of my treatment?
13. Should I think about genetic testing?
14. Should I get a second opinion? How do I do that?
15. Should I think about taking part in a clinical trial?

Slide 12- Questions to Ask

So as we started, and throughout, so far these slides have been talking about questions to ask. The basis of all communication is question-and-answer. It's sharing information. And questions that you ask are very specific to different times throughout your cancer treatment or your cancer journey. So these questions, by the way, are available to you on this slide deck. They're also available at cancer.org, the American Cancer Society (ACS) website. When you're told--and by the way I have 15--I think I have three or four slides about this. I don't expect, or no one does, that you'll ask every one of these questions. Go through them. What's pertinent to you? What do you need to know? Maybe you ask them at different times.

Certainly, when you're told you have cancer, that initial information, here's some really important questions to ask. Exactly what kind of cancer do I have? How do I get a copy of my pathology report? Remember that previous slide about getting your information because your pathology will tell what kind of cancer you have, and you might want to refer back to that time and again. Where is my cancer located, and is it in one place? Is it centrally, focally located, or has it spread elsewhere? Before, has it gone beyond where it first started? What's my cancer stage, and what does that mean? Cancer Stage I through IV, Stage IA, IB, IIA, IIB, what does that mean? How does that--does that drive my treatment? Does it change what my treatment options are? How does it affect my treatment, and what's my long-term outcome? What does it look like? What's the future? Prognosis of the future. What's going to happen? Again, that elephant in the room; what's my chance of survival? You know, based on the cancer I have right now, and you told me where it's located, or whether or not it's spread and what the stage is, so what does that say about my living based on what you're seeing right now? It's okay to ask--maybe up front, maybe number eight should have been earlier--but how much experience do you have treating this type of cancer? Have you seen a lot of patients diagnosed like me? Maybe that's an easier

way of saying, how much experience as opposed--have you seen a lot of patients who have this diagnosis, Doc? And find out--excuse me--will I need other tests before we decide on treatment? What are those tests? What are my choices? Do you recommend a treatment? Why do you recommend it? What are you thinking about that?

An important question is what's the goal of my treatment? What are we heading towards? What do we want done here? Is the goal to cure my cancer? Is the goal to let me live a long, productive life, quality-wise, quantity-wise? What are our goals here? And that may not be able to be answered right away. You may need more information moving forward. Should I think about genetic testing? You know there's two types of genetic testing. There is a germline of familial genetic testing, and that's testing for the genes that your parents have passed down that might give you a predisposition or a statistical higher chance of having certain cancers. We can always thank Angelina Jolie and all the Hollywood gossip and the focus on her, but for bringing attention for something like the BRCA1 or 2, the BRCA1 or 2 gene. That's about familial testing. The other type of genetic testing is testing the genes that make up your cancer. That's a very different--that's the gene type that is literally in the cancer cell, and that can drive treatment. We've heard about that with is it an EGFR gene in that cancer because in certain lung cancers and other cancers that will determine what kind of medicine and treatment we give you, or not give you. So two different types about genetic testing. Be clear when you ask that.

It is okay to ask your doctor, should I get a second opinion? If you can't ask your doctor that, or your doctor pushes back and you have a problem with that question, get another doctor. Good doctors welcome second opinions. How do I do that? And very importantly, do I need, or should I take part in a clinical trial? Should I be thinking about that? Clinical trials are very exciting, and remember you always are going to get the standard of care. No one's going to withhold care from you during a clinical trial.

Questions to Ask

When deciding on a treatment plan:


1. What are the chances the cancer will come back after this treatment?
2. What would we do if the treatment doesn't work or if the cancer comes back?
3. Will I be able to have children after treatment?
4. How much will I have to pay for treatment? Will my insurance cover any of it?
5. How long will treatment last? What will it involve?
6. Where will treatment be done?
7. What risks and side effects should I expect?
8. What can I do to reduce the side effects of the treatment?
9. How will treatment affect my daily activities?
10. Will I be able to work during treatment?
11. Will I lose my hair? If so, what can I do about it?
12. Will the treatment hurt?
13. Will I have any scars?



Slide 13- Questions to Ask

So those are some questions up front when you're first diagnosed. Then questions more specifically, as you're deciding on a treatment--and some of these we may be repeating, but you want to know what are the chances this cancer will come back after treatment? And if it does, what treatments do we get then? Will I be able to have children after treatment? How will I pay for this? And this may be a question that you preface by saying Doctor, is there someone other than you I need to speak with about paying for my

treatment, my insurance coverages, my co-pays? We're having some family problems. Is there local or national assistance to help pay for my care? You want to ask where your treatment will be done. Of course, you want to know about risks and side effects. Often if you're being treated in a specific cancer center, one that might be attached to a hospital, there may be an intake nurse, or a chemotherapy nurse, or a radiation nurse, or a treatment nurse, or a nurse practitioner that you can ask these treatments of. And again, that goes back to that question, who's on my team, and what do they do? And then you'll know who to ask these questions of. How do I reduce side effects? Is my treatment daily, and will it affect my daily activities? Can I work? Can I exercise? Will it hurt? If I lose my hair is there anything I can do about that, if that's important to you. Those are all upfront questions as you're deciding on treatment. They'll help you make an informed decision, and they'll help members of your healthcare team understand what you need to know, what is or isn't important to you.



Questions to Ask

Before treatment:

1. What should I do to get ready for treatment?
2. Will I need blood transfusions?
3. Should I change what I eat or make other lifestyle changes?

During treatment:

1. How will we know if the treatment is working?
2. Is there anything I can do to help manage side effects?
3. What symptoms or side effects should I tell you about right away?
4. How can I reach you on nights, holidays, or weekends?
5. Do I need to change what I eat during treatment?
6. Are there any limits on what I can do?
7. What kind of exercise should I do, and how often?
8. Can you suggest a mental health professional I can see if I start to feel overwhelmed, depressed, or distressed?
9. Will I need special tests, such as imaging scans or blood tests, and how often?

Slide 14- Questions to Ask

Before treatment you want to know if there's anything you need to do to get ready for treatment. You'll want to know do you need blood transfusions? Do you have to change the way you eat? Or certain lifestyles, do they need to be changed? Do you stay up late? Do you not get enough sleep? Do you exercise? How much? During treatment, other specific questions; how do you know if the treatment is working? Is there anything I can do to help manage my side effects? Look for symptoms and side effects. What should I tell you? What's important and what isn't? If I get a twinge or a pain, what's the difference?

Important, again, when we talked about how does your office work and what should I know, how do you reach your healthcare providers at off-hours, so to speak, nights, holidays or weekends? That's important to know. Do you need to change what you eat? Again we ask that, or exercise, are there limits to what you can do? What kind of exercise? Notice I don't say do I stop exercising? More often than not we want you moving most of the time. But you know what, you may walk three miles a day, but during treatment we may want you to walk from your front door to your mailbox and back, or we may want you to walk from your living room to your kitchen five times a day. Ask, what should I be doing? What recommendations? Are there experts to help me? Whether it's a nutrition expert, a registered dietitian, whether it's a physical or occupational therapist, how about your oncology social worker? Obviously I'm a

little biased towards oncology social workers, but who can you see if you start to feel overwhelmed, overly anxious, depressed or distressed? Who can I talk to just to focus on how I'm feeling, not necessarily on my treatment?

But here's a caveat, and it's really important. If you're in treatment you really want to be speaking to an oncology social worker, a social worker that understands what it means to be a cancer patient and has the training and expertise in the different types of cancer treatment. I think that makes a huge difference in how they can help you and what they can do for you. I will often say to someone who's telling me that they're crying on and on and on and feeling very depressed, or distressed, or anxious, the first question an oncology social worker--the first question I ask, tell me about your treatment and what medications are you on because I know about those medications, and I know about their side effects. And if I don't, I have immediate access to numerous other team members that I can quickly ask. So before I launch into psychotherapy and support, verbal talking support groups, I first am always going to check out the medical end of things. That's important.

And lastly, during treatment what kind of tests do we have going on during my treatment because people are often surprised to find out they're not just coming for treatment, but the day before they have to come for tests ,or a week before an imaging, a scan? How's treatment working? Let's take a look at a scan and see if we have any reaction to that treatment. So ask those questions. A lot of stuff to know, isn't it? A lot of questions to ask. That's why it's really, really helpful to have this list. Write them down, pull the ones you need, bring it with you, and keep referring back to it because before, during treatment certain questions, and then after treatment there are certain questions to ask.

Questions to Ask

After treatment:

1. Do I need a special diet after treatment?
2. Are there any limits on what I can do?
3. What kind of exercise should I do now?
4. What type of follow-up will I need after treatment?
5. How often will I need to have follow-up exams and imaging tests?
6. What blood tests will I need?
7. How will I know if the cancer has come back? What should I watch for?
8. What are my options if the cancer comes back?



Slide 15- Questions to Ask

After treatment when asking do I need a special diet after treatment? Are there any limitations? Have you had surgery? Have you had transplant? Do you have bone involvement? What are the limits? What exercise should I be doing now? Always some way to move, whether it's tai chi for balance, soft stretching chair yoga perhaps, again walking, if you're fortunate enough to have access to a pool. But be careful. A lot of doctors will tell those in treatment, chemotherapy or radiation, that they don't want you in a public pool. So always ask.

It's important to ask, how often will I need follow-up exams and imaging tests? What type of tests will I need? How do I know if the cancer is coming back? What should I ask for? You know more often than not I hear this time and again that folks will equate the anxiety before when they were first told they had cancer with the anxiety when they're all done with care and treatment, if they're done, or they're getting a break. That in-between time during treatment, it's like okay, I got it now. I know it's expected. I know I have this treatment on this day, or I go at this point. And there's kind of a lull. I see what's happening. If I'm done, if there is an after treatment or there is a break in treatment or a change, it's like oh, wait a minute. This is very anxiety-provoking. I don't know what's going on now. Maybe you're not seeing your practitioners as often. Who's checking you? Who's following you? That's why there's something called survivorship care plans for folks who have a break in treatment or after treatment so you can have some of these questions answered. Or turn them around. If you have ongoing, lifelong treatment what do I need to know throughout my treatment? Important to know.

Questions to Ask



Along with the sample questions I've shared, think of the specific questions you and/or your loved ones may have. For instance, you might need to know more about how long it will take to recover from surgery so you can plan your work schedule. Or, you may need to ask about insurance coverage or how you can get help paying for treatment.

Questions to Ask My Doctor About My Cancer, American Cancer Society, 2013

Slide 16- Questions to Ask

What I'm saying is along with all of the sample questions that I've shared with you, we also want to think of what's specific for you and your loved ones. I mean you might be working. So you might need to know how long you have to recover from surgery so you can plan your work schedule. You might have very specific insurance questions. You might have small children. You may have grandchildren. You may have a trip planned. You may live in a mobile home, you know, where you're going around the country and going to different places. How do you manage your care that way? So your questions need to be very specific for you and your loved ones.

Take Action!

Many of us have a hard time talking frankly with our doctors and other people on our health care team. Some of us grew up in a time when patients didn't ask a lot of questions or tell doctors what they wanted and expected. Today, we encourage patients to speak up and take a very active role in their own healthcare.

As a Patient, you have:

- A right to have a voice in your treatment
- A right to have your questions answered

Asking questions and talking honestly about what **you** need and expect helps build a strong relationship with your health care team.



LLS: Getting the Best Health care at Any Age

Slide 17- Take Action!

You know, all of this, when we talk about communication and we talk about questions to ask, it's really about taking action. Many of us have a hard time speaking very frankly with our physicians or others on our healthcare team. You know, some of us are of an age where we grew up in a time when you really didn't question your doctor. You didn't tell them what you wanted or expected. You know, I'm of an age, and those of you who are joining me on the phone who are and have access to US television at least, you know remember Dr. Marcus Welby, or Dr. Kildare, or Dr. Ben Casey, they diagnose you, they tell you what's wrong, they tell you what you should do, and on you go. Things are different today. We really, really encourage patients to speak up and take a very active role in your own health care.

You know as a patient you have a right to voice, have a voice in your treatment. It's very important. This is called patient-centered care. You have a right to have your questions answered. Asking questions and talking honestly about what you need, that helps build a strong relationship with your healthcare team. Tell people what you like and don't like about your treatment on your team. Tell your team members. If you don't understand the answers, ask them again, and keep asking until you do understand and you're satisfied with the information you receive. But make sure that you don't to keep asking because you want a different answer. Maybe you have a cancer that can't be cured, but you keep wanting them to tell you it can. That's not helpful, and your team won't do that, and it will cause frustration and friction between you and them. So make sure that if you don't understand the answer to a question, not that you're not getting the answer you want but you don't understand the answer you're getting, that you keep asking until you do.

Consider a second opinion. Find out more about your cancer from your doctor or reliable websites, reliable websites. A reliable--what's a reliable website? I'll tell you. Its URL, its address ends in *.org*, which means it's a nonprofit, *.edu*, which means it's usually from a university-based program, *.gov* in the US. That means it's from the government. That's either the National Cancer Institute (NCI), the National Institute of Health (NIH), National Comprehensive Cancer Network (NCCN). These are reliable websites that can provide educational material, programs and services, *LLS.org*, support for people with cancer and their families.

But as always, any information you get on the internet, especially if it's telling you to do something or take something, you need to bring that back to your doctors or nurses. We all have experienced someone's personal opinion, some blog. Blog? Right, blog, or some site that ends in .com. Maybe they're selling something that's saying, oh, if you only take this this will really work for your cancer. Anything you ingest, over-the-counter, anything, can affect the treatment you are getting, so please make sure you bring that information back to your physician, your nurses and your team.

Talking with your Treatment Team

Types of personal information that may be helpful to your doctor:

- Your occupation and the degree of physical exertion or mental stress it involves.
- Close relatives who have had cancer and what type of cancer they had.
- An idea of how much you know about cancer and its treatment.
- The degree to which you are affected by family or financial problems.
- Your hobbies and other interests.
- Your goals regarding your quality of life during and after treatment.
- Whether you have children or plan to have children.

Teamwork: The Cancer Patient's Guide to Talking With Your Doctor. NCCS, 2004

Slide 18- Talking with your Treatment Team

When you talk with your treatment team, when you're giving them important information, the information you give will help you grow a relationship with them. They need to know about you. What do you do? If what you do causes great physical or mental stress, they need to know that. They need your family history, close relatives who've had cancer. How much do you know about cancer and its treatment? You can imagine when I go in I'm a cancer survivor, and when I go into a new doctor, you know I let them know right away what my background is. When my mother or my sister goes into their doctor, they don't, and they let them know they don't know much. Let your doctor know what's going on with your family and financial problems. They may not be the person who can assist you, but they can direct you to who can. Don't expect them to do it. It's a team. We call it a healthcare team for a reason. There are others.

Let people know what your hobbies and your interests are, what your goals are. What do you want for quality of life during your treatment? Certainly, whether or not you plan to have children or not. You want to ask and take advantage of services offered at your doctor's office, at a hospital, a cancer center. Many different resources are available. It can include counseling, patient navigation services, support groups, nutritional counseling, fitness movements, movement classes. You know, ask about all of these things. They need to know what's important to you, and the only way they're going to know is if you tell them.

Teamwork Barriers

Patient Barriers

Physician/Treatment Team Barriers

Slide 19- Talking with your Treatment Team

You know, when we talk about teamwork, as we start to wind down, let's recognize the barriers because all the information I can share with you or anyone else about getting the best healthcare, communicating with your healthcare team, you have to recognize the barriers. See what barriers you own as the patient, and that's important. You know, perhaps you're bringing way too many lists of questions that can't be answered, or maybe you're getting angry and you present yourself in such a manner that people back off and can't communicate or are afraid to say the wrong thing to you. Perhaps you smile and nod your head like the gentleman on the left under patient barriers, showing oh sure, everything's great, but really thinking it isn't. Maybe you're not hearing me. Those are patient barriers. You're not saying what you think. You're bringing too many questions and using up time, and you didn't prioritize. You're getting angry and not being a team player.

And of course then there are physician barriers, and those are very important. The doctor on the right with his hands out saying, I know everything; I'm the doctor, or a physician having to literally write a book when doctors don't listen. That's the physician and treatment team barriers, if they're not hearing you, if they think they're the experts. You know, it takes a team effort for you and your healthcare providers to work together to make sure your treatment is safe and appropriate. They need to know what you want, and you need to ask what you need from them.

Saying and Hearing: Tips For Understanding Your Doctor

- Use "I" statements.



- Be assertive.



- If something is unclear, try repeating it back to your doctor.



CancerCare: "Doctor, can we Talk?" Tips for Communicating with Your Health Care Team. Feb. 2017

Slide 20- Saying and Hearing: Tips For Understanding Your Doctor

Use I statements. Tips for understanding, use I, not you. Doctors using medical language isn't familiar. We talked about that. But if you're having trouble understanding, here's how you use an I statement. You say I don't understand, Doc. Do me a favor. Say that again for me. Use different words. That's much more effective than saying, you're being unclear. You're not making yourself understood. Be assertive once you don't know or understand something. Don't be afraid to speak up and ask. Make your questions specific. Speak in bullet points, and brief. But if you continue to be confused or overwhelmed or you feel a question hasn't been answered, you may want to ask your doctor or nurse, is there another time when we can talk about this in more detail? I'm just not getting what I need, and I understand you have patients that are waiting to see you.

And again, how do you speak? Maybe they want to speak by phone later in the day, or email. And if something is unclear, try repeating it back to your doctor. This is called mirroring, and it's really sometimes very effective in clarifying what's being said. I mean you can say something like, so you mean I should do this, or so I think what you're suggesting is that I do this. If you understand better with visual aids, have your doctor write down the information, or ask to see x-rays or slides and have them point to you and explain.

It's All About the Quality of **YOUR** Life

"The relationship you have with your health care team can make a big difference in how you cope with these challenges. Research shows that people who have good communication with their health care team are more satisfied with their medical care than those who do not. They also tend to fare better emotionally and better manage symptoms such as treatment side effects and pain."



Sarah Paul, LMSW
Oncology Social Worker, CancerCare

Slide 21- It's All About the Quality of YOUR Life

In the end, this is all about you, the patient, your loved ones, your family and how you communicate to get the best care you can get. It's all about the quality of your life, and I'd like to quote my colleague, Sarah Paul, from Cancer Care: The relationship you have with your healthcare team can make a big difference in how you cope with these challenges of being a cancer patient. Research shows that people who have good communication with their healthcare team are more satisfied with their medical care than those who do not. They also tend to fare better emotionally and manage pain and symptoms and treatment side effects much better.

Communication

*With communication comes understanding and clarity;
With understanding, fear diminishes;
In the absence of fear, hope emerges;
And in the presence of hope, anything is possible.*

Ellen Stovall

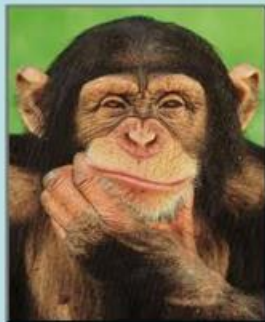
Past President & CEO, National Coalition for Cancer Survivorship



Slide 22- Communications

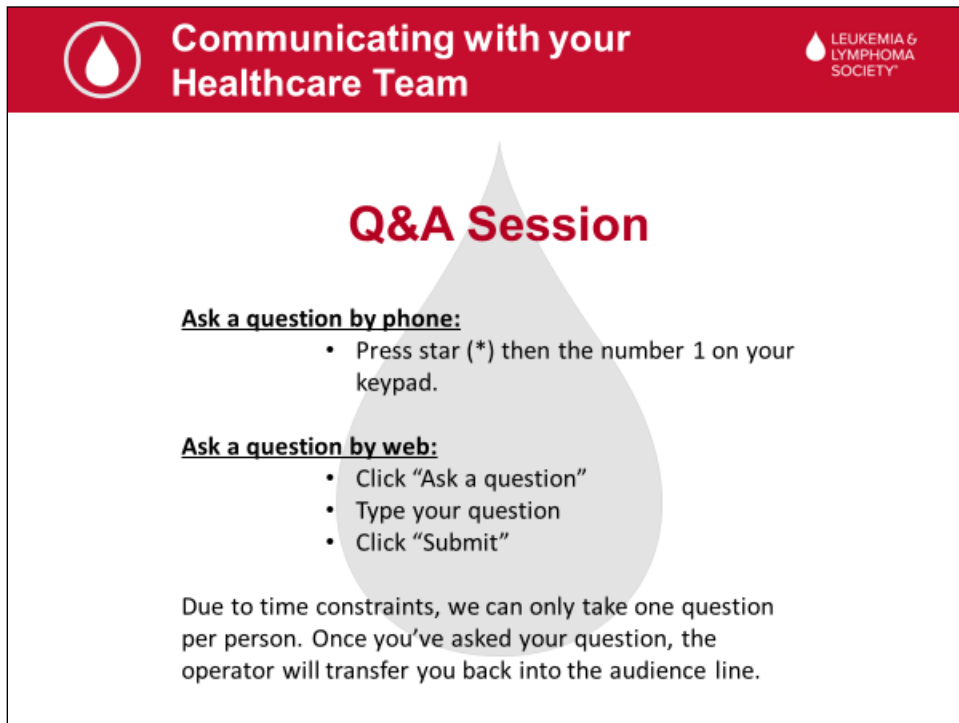
It is about you and the quality of your life because with communication comes understanding and clarity; with understanding, fear diminishes; in the absence of fear, hope emerges; and in the presence of hope, anything, anything is possible.

Hmmmmm.....! Questions?



Slide 23- Hmmmmm.....! Questions?

I thank you so much for allowing me the time to share this information with you, and I'm more than happy to turn this back over, I believe to Lizette, and take questions.



Communicating with your Healthcare Team

Q&A Session

Ask a question by phone:

- Press star (*) then the number 1 on your keypad.

Ask a question by web:

- Click “Ask a question”
- Type your question
- Click “Submit”

Due to time constraints, we can only take one question per person. Once you’ve asked your question, the operator will transfer you back into the audience line.

Slide 26- Q&A Session

Lizette Figueroa-Rivera:

Thank you so much, Mrs. Sachs, for your very informative presentation.

Lizette Figueroa-Rivera:

Our first question comes from the web. It comes from Patricia. She asks, does Medicare cover appointments with an oncology social worker?

Alison Mayer Sachs:

Oh, that’s a wonderful question. If your oncology social worker in the U.S. has the designation of LCSW, licensed clinical social worker, yes, there should be some coverage. You have to check with the oncology social worker or the cancer center. Those can be 30-, 45-minute or 60-minute appointment times.

Lizette Figueroa-Rivera:

Thank you. And we’ll take the next question from our web audience. Kathy asks, how much detail does my oncologist need about symptoms? What are important circumstances to share with my doctor versus what could be considered not so important? I don’t want to be perceived as a worrywart.

Alison Mayer Sachs:

Oh, Kathy, I hear this question all the time, and I really thank you for asking it. It’s a really important one. I think the first rule of thumb truthfully is to ask your doctor or nurse what do they expect to hear from you because honestly they’re each different. I mean I have one doctor in my cancer center, she wants to know everything. If you have a twinge, she wants to know about it. I have other doctors who just say look, if you’re in pain to the point where you’re going, oh my God, this really hurts, you need to call and ask us about it. If you’re in pain to the point where you can’t stand up, or you can’t take it, you need to go to the emergency room. So it really is what does your practitioner expect?

We know about the pain scale, so you can use that. It is really helpful. For those of you who don’t know about it, it’s rating your pain from 0 to 10, 0 being no pain, 10 being excruciating, you can’t barely take a breath it hurts so badly. So if you can rate your pain that will make a difference. Ask your doctor about that, or your nurse. Hey, if I’m experiencing this pain and it’s a 5 or above, what do you want me to do?

The other is don't ever worry about being perceived as a worrywart. You know a smile and a warm attitude goes a really long way, and a lot of forgiveness with staff that might be busy. By just saying hey, you guys, I know I don't want you to think I'm being a pain, but really a quick question. As you move through your treatment you will more often than not really start to understand your own body, it's response to what's going on with your cancer treatment or how it feels, and then sort of start to know hey, this does not feel right. But you know what the old saying is, always err on the side of caution. Just ask.

Lizette Figueroa-Rivera:

Thank you. And we'll take the next question from the phone audience, please.

Operator:

Our next question comes from Christine, calling from Virginia. Please state your question.

Ms. Christine:

Hi. I am the grandmother of a child who has ALL, and his father has epilepsy. The mother left the family two months before the diagnosis, and so I am the backup person for my grandson, and I'm just wondering do I have rights to have conversations with my grandson's doctors if my son ends up having seizures and is unavailable?

Alison Mayer Sachs:

Hi, Christine. Well, first of all, how fortunate is your family to have you? God bless, really.

Ms. Christine:

Thank you.

Alison Mayer Sachs:

That's quite a roll to be thrust into, and it sounds like you take it seriously and you are a gift to them. That's wonderful.

Ms. Christine:

Thank you.

Alison Mayer Sachs:

The easiest --you're welcome. The easiest answer to that, dear, is to get it done legally. The power of healthcare attorney is one way we call it, something to call it, and really you can, if you're proficient on the web you can look it up in the state you live in. Every state has them. This way a discussion with your son, I'm assuming that all is okay and you two have a good relationship. And say to him hey listen, you know, God forbid you're in the middle of a seizure--okay--I need to be able to speak for you. So first of all, get on the same page with your son that you agree what you would, you know, about your grandson and his treatment and what's going on. Your grandson is under 18?

Ms. Christine:

He's seven years old.

Alison Mayer Sachs:

Oh, okay. So yeah, get clear with your son, and then just get--have a legal document that indicates that you can speak for your son in the care of your grandson when your son is unavailable. And you can ask the doctor's office, as well.

Ms. Christine:

And it's called power of healthcare, what?

Alison Mayer Sachs:

Attorney.

Ms. Christine:

Attorney, okay.

Alison Mayer Sachs:

Power of healthcare attorney.

Ms. Christine:

Thank you.

Alison Mayer Sachs:

And it basically gives you the right to speak in lieu of your son for your grandson's care, okay?

Lizette Figueroa-Rivera:

Well thank you, Christine, for your question, and you can definitely contact us here at The Leukemia & Lymphoma Society at our Information Resource Center, and I will be giving you that number a little later for other support services and assistance. And our next question does come from the web from Chava asking, any suggestions about how to effectively communicate disagreement with my doctors?

Alison Mayer Sachs:

You know, the first thing is if you have a social worker on site I would first sit with the social worker, Chava, and go through what the disagreements are about. Make sure that you're clear on how to present them, and make sure they're justified. You know, in the middle of care, and again, I speak as a cancer survivor so I think it's fair for me to say at least from my experience, you know it's pretty heightened anxiety time as a cancer patient. And with heightened anxiety comes sometimes a little sensitivity. So please just first, whether it's a dear friend you trust--but you know a friend might, or a family member might just agree with you.

So that's why I'm suggesting sit with a social worker. Say you know, this is what's going on with me and the doctor. These are my disagreements. Can I just run this by you to see if it sounds logical? And then maybe they might even help you practice how you use those I statements with your physician. Make a separate appointment if you have to, appointment time. Write down your concerns. And then make sure you're even writing them in I statements. And then sit down and say--start it off by saying you know, Doc, this is not an easy conversation for me, but you're my doctor, and it's important that you and I be on the same page. So this is what I'm feeling like we're not on the same page about, and I'm concerned.

So use those I statements. Use, possibly if you have one, an oncology social worker to practice with or to make sure you're focused and what your concerns are, and make that appointment and get it out there. If you can't resolve it, get another doctor.

Lizette Figueroa-Rivera:

Thank you so much. And our last question today comes from Lupita. She is asking, do all cancer patients receiving treatment, seeing an oncologist, have a healthcare team? Who are the people that are normally a part of that team?


Alison Mayer Sachs:

Oh, Lupita, thank you for reminding me to be more concise and specific when I speak. I thank you for that, and I apologize. You're absolutely right. There are solo practitioners, solo docs who practice on their own, not so many anymore. There's still--the majority, by the way, of cancer care is given in private

practices. They tend to be a group of doctors, but more often than not, yes, most cancer patients, whether they're in a private group practice or in a cancer center, most patients will have a team. It's their doctor, a nurse, maybe a medical assistant, you know the person that comes in, takes your blood pressure and your weight. Maybe there's a front desk person. There could be lab technicians, someone who takes, draws your blood. The bigger centers, even the community cancer centers, will have an oncology social worker or access to one. So it all depends on where you're treated, and I think, Lizette, this is something you all could be very helpful with. If Lupita is being treated in the U.S., you know, find out where she's treated and point her in the right direction if she's missing any of that treatment team.


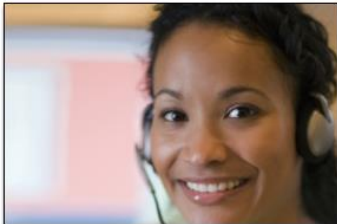
Lizette Figueroa-Rivera:

Definitely. We could definitely do that, and of course, Lupita, I'm going to give you the number to our Information Specialists, and they can actually help you with finding out who is in your treatment team, and if you need assistance in contacting them we can help you.



The Leukemia & Lymphoma Society Offers:

- **Information Resource Center:** Information Specialists, who are master's level oncology professionals, are available to help cancer survivors navigate the best route from diagnosis through treatment, clinical trials and survivorship.
 - EMAIL: infocenter@LLS.org
 - TOLL-FREE PHONE: 1-800-955-4572
- **Free Education Booklets:**
 - www.LLS.org/booklets
- **Free Telephone/Web Programs:**
 - www.LLS.org/programs
- **Live, weekly Online Chats:**
 - www.LLS.org/chat



Slide 27- The Leukemia & Lymphoma Society Offers

Thank you so much, Mrs. Sachs, for sharing your expertise with us today. And we hope this information from today's program will assist you and your family, in your next steps.

As I said, if you weren't able to get your question in today or submitted a disease-specific question, you can contact an Information Specialist at The Leukemia & Lymphoma Society at 1-800-955-4572 from 9 AM to 9 PM Eastern time, or you can reach us by email at infocenter@LLS.org, and Information Specialists are available to answer your questions about treatment, including clinical trials, or answer other questions you may have about support as well as financial assistance for treatment. And we do invite caregivers to contact us also.



The Leukemia & Lymphoma Society Offers:

- **Support Resources:** LLS Community, discussion boards, blogs, support groups, financial assistance and more: www.LLS.org/support
 - **NEW LLS Podcast, *The Bloodline with LLS!*** Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients. www.thebloodline.org
- **Education Video:** Free education videos about survivorship, treatment, disease updates and other topics: www.LLS.org/educationvideos
- **Patti Robinson Kaufmann First Connection Program:** Peer-to-peer program that matches newly diagnosed patients and their families: www.LLS.org/firstconnection
- **What to ask:** Questions to ask your treatment team: www.LLS.org/whattoask



Slide 28- The Leukemia & Lymphoma Society Offers

Again, we'd like to acknowledge and thank Genentech & Biogen, Bristol-Myers Squibb and Takeda Oncology for support of this program.

**THANK
YOU FOR
PARTICIPATING!**

We have one goal:
**A world without
blood cancers**

LEUKEMIA &
LYMPHOMA
SOCIETY®

Slide 29- Thank you for participating!

On behalf of The Leukemia & Lymphoma Society, thank you so much for joining us for today's program. Take good care.