

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Monica Answers YOUR Questions About Cancer and the Law'

Description:

Did you know that if somebody is eligible for Medicaid and also eligible for COBRA coverage, some states may actually pay their private COBRA premium? Learn about this and more as Alicia and Lizette chat with Monica Bryant and ask her questions that many of *you* have asked! Monica is the Co-Founder and Chief Operating Officer for Triage Cancer, a national non-profit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials and resources. Topics on this episode include: the difference between Medicare and Medicaid, Medigap plans, laws surrounding debt collectors, understanding deductibles and out-of-pocket maximums, COBRA, employment rights, appealing a denial notice from a health insurance company and more.

Transcript:

Alicia: Welcome to The Bloodline with LLS. I am Alicia.

Lizette: And I am Lizette. Thanks so much for joining us on this episode.

Alicia: Today's episode will be slightly different in that the questions today have been asked by our patients and caregivers on LLS Community. LLS Community is just that; a community of blood cancer patients and caregivers. LLS created a social online platform to provide support, trusted information and resources, and help patients and caregivers feel connected to one another. We believe that one should not have to face a blood cancer diagnosis alone so we hope that those listening will visit www.lls.org/community and join a vibrant and interactive community.

Now, to tell you a little about our guest today, Monica Bryant is a cancer rights attorney, speaker and author dedicated to improving access to and availability of quality information on cancer survivorship issue. Monica is the co-founder and Chief Operating Officer for Triage Cancer, a national non-profit organization that provides education on the practical and legal issues that may impact individuals diagnosed with cancer and their caregivers, through events, materials and resources. Throughout her career, Monica has provided hundreds of educational seminars, written articles, blogs and co-authored a book published by the American Bar Association called Cancer Rights Law: An Interdisciplinary Approach. Thank you so much for joining us today, Monica.

Monica: Thank you so much for having me. I am happy to be here.

Alicia: And Monica is no stranger to The Bloodline. We actually recorded an episode with her titled, What You Need to Know About Cancer and Health Insurance. So, we encourage you to listen to that episode by visiting www.thebloodline.org and selecting 'Episodes' and finding again the episode titled What You Need to Know About Cancer and Health Insurance.

Monica, I was on americanbar.org and I was reading an article in which they quoted your sister, Joanna Fawzy Morales, who is also a cancer rights attorney (yes; listeners, 2 sisters are cancer rights attorneys. How awesome is that!) and she mentioned that because the health and legal issues can be so intertwined, there is a great deal of opportunity for attorneys to advocate on behalf of individuals diagnosed with cancer, and their families, and to help them navigate through a plethora of systems and procedures. She goes on to say that while people diagnosed with cancer face a variety of issues with their health insurance, finances and employment, many don't think of these as legal issues that require a lawyer. Can you go into more detail about that?

Monica: Absolutely. So, one of the things that we hear frequently is people who are trying to navigate all of these things that come up after a cancer diagnosis, like health insurance and what to do about their jobs, and how can they take time off; and then if they have to take time off, what are they going to do for income? And so, all of these things come up and that people now have to become experts in navigating; and those are actually all rooted in laws. Our right to purchase health insurance is given to us through a law. Our right to take time off or to have protections in the employment arena come through laws, but most people don't think of the law when they think about how to navigate these systems. So, that's really what we are trying to do at Triage Cancer is to empower individuals to understand the law. That it doesn't have to be this scary thing that you need a lawyer to help you through. And then once they understand the laws, that they feel empowered to become their own advocate to navigate these systems and exercise the rights and benefits that they're entitled to.

Alicia: Monica, I like that you mentioned, become an expert and I think that is something that is just so mind-blowing to me because health insurance is so complex and, you know, the cancer diagnosis is so complex so you are thrown into this world and you have to think to yourself; "okay, how am I going to actually survive with this diagnosis?" And then to have to understand your diagnosis alongside something so complex like health insurance. When you say, "become an expert", it is just so true that you have to completely shift gears and acquire so much knowledge so quickly. And sometimes it is really time against the clock, right?

Monica: Absolutely; and, you know, we always joke that there should be a class in high school on understanding health insurance and finances because it's something

that every single one of us in this country has to navigate at some point, but none of us are ever taught how to do that.

Alicia: Right; right.

Lizette: It's true.

Alicia: That's so true. I mean, in high school, we learn so many other things and I feel that this is something that we should learn relatively early.

Monica: Yeah, it's part of that whole Adulting 101 series, right?

Alicia: Hmm; hmm; exactly. So, jumping into Medicare and the questions that we receive surrounding that, Medicare is a national health insurance program in the U.S. It began under the Social Security Administration and now administered by the Centers for Medicare and Medicaid Services and it provides health insurance for Americans aged 65 and older, but also for some younger people with disability status as determined by the Social Security Administration. So, Monica, to kind of give our listeners a basic, practical understanding of Medicare, the questions we got were, of course, what is it? What does it mean to a cancer patient and what's the difference between Medicare versus private insurance?

Monica: Sure. So, Medicare, again, is a federal program and it's for individuals who are over 65 or have been receiving Social Security disability insurance for 2 years; and Medicare is broken up into 4 parts: Part A provides in-patient hospital insurance. Part B is going to be medical insurance so whether you see the doctor, or lab work, or tests. Part D is for prescription drugs. Now, there is a misconception for many that Medicare is actually free, once you reach a certain age or you have a disability, and that's not true. In fact, there are going to be different costs for each of the different parts. So, for some people, it is challenging to have to navigate 3 different parts with 3 different cost structures and so an alternative to that was created in Part C, also known as Medicare Advantage plans. And these operate as HMOs, or PPOs, and they look a little bit more like what people are used to with private or employer-sponsored insurance where all of your care is managed under one plan. So, you sort of have 2 lanes you can drive in. You can get all of your services in a Part C Advantage plan or you can have the separate parts of A, B, and D. There's pros and cons to all of this. When you have Part A and Part B, that is referred to as original Medicare; and with original Medicare, you can go and see any doctor in the country that accepts Medicare. When you compare that with a Part C, or an Advantage plan, those are going to have smaller networks of providers and so you are going to have to make sure that you see one of those providers in that network. Of course, there are many, many more differences and pros and cons, but that's sort of the high-level overview.

Lizette: So, does Part C also include what Part D would include which is the medications?

Monica: Great question! It depends. There's many Part C plans that include prescription drug coverage, but if somebody chooses a Part C plan that does not include prescription drug coverage, they would have the opportunity to pick up a stand-alone Part D plan.

Lizette: And Part D, is that the one that you must pay for. I always thought that Part A and Part B.

Monica: So, Part A is typically what we refer to as premium-free for most Americans who have worked and paid into the system. There are still some other costs like co-insurance associated with Part A, but it's typically going to be premium-free and premiums are what you pay monthly just to have the insurance. With Part B, there is a monthly premium, even if you paid into the system. This year, for most people, the Part B premium is \$135.50 a month. And then, Part D premiums are going to depend on the plan chosen so they vary depending on which plan people choose. I believe the national average this year is somewhere around \$33 a month for Part D plans.

Alicia: We received a question, Monica, that said, "if I move to a different State, does my Medicare supplement insurance go with me?"

Monica: So, first, let's talk about supplemental insurance. So, when somebody has original Medicare, which again is Part A and Part B, Part B has a 20% co-insurance, which means that after the person has paid their deductible, they are responsible for 20% of all of their medical costs for the year; and there is no limit to that. There is no out-of-pocket maximum. And when you start thinking about cancer care and you realize that some or many chemotherapies are covered under Part B, that person is going to be paying 20% of every single chemotherapy that they receive. So, that can get incredibly costly. So, one way to deal with that is by purchasing an additional insurance plan called a supplemental insurance plan or a Medigap plan. And the Medigap plans can pick up those extra out-of-pocket costs. Now, Medigap plans, you have choices; and they are identified by letters A through N and where that gets really confusing for people is that we can't confuse Medigap plans A through N with Medicare Parts A through D. So, because they both use letters, it's really confusing for a lot of people as to what they have and what it covers. Now, these Medigap plans are very, very useful because they help cover those out-of-pocket costs and you could only get them when you have original Medicare. So, remember I said with original Medicare, you can go see any doctor in the country that accepts Medicare. So, that Medigap plan, also known as a supplemental plan, will go with you even if you change states. That's very different than a Part D plan or a Part C plan because those are going to have networks and, when you move, you may actually be moving out of those plans' networks and so you would actually have to find new plans in those cases.

Lizette: Now, somebody is diagnosed with cancer and they don't have the supplementals to pick up that extra, you were saying, 20%, can somebody sign up for that at any time or is there a certain time that you have to sign up for that?

Monica: So, Medicare has a bunch of different enrollment periods depending on where you are in the process, but every single year between October 15 and December 7 is the Medicare open enrollment period. And this is where people have the opportunity to switch from original Medicare to a Medicare Advantage plan, or maybe from an Advantage plan to original Medicare, or they can also pick up a Medigap plan. Now, of course with everything we talk about, the devil is in the details. So, when someone first becomes eligible for Medicare, they have what's called a guaranteed issue for the supplemental plan, which means they have to be sold the supplemental plans and they can't be charged more because of pre-existing conditions. But, let's say they didn't pick it up when they were first eligible; now, they have a cancer diagnosis and they think this might actually be very helpful for me. They can shop around for a Medigap plan, but those Medigap providers can actually charge people more because of their pre-existing condition and they can impose something called "a pre-existing condition exclusion period". So, that can be up to 6 months where the Medigap plan isn't going to cover anything related to their pre-existing condition. And what we see happening is people find out this information and they think, "well then, what's the point. If it's going to be 6 months that they are not going to cover anything related to my pre-existing condition, it doesn't make sense for me to pay to have this plan." But we really encourage people to do the math because, if you think about it, even if it's 6 months that Medigap plan doesn't cover anything; if someone is getting chemo for a year, or for 2 years, or other types of cancer treatment, having coverage for the second 6 months of the year and then moving forward can still save thousands of dollars. So, we really want people to not just sort of discount picking up these plans because of that 6-month exclusion period; that they should do the math.

Lizette: Sure. I know that you mentioned a pre-existing condition in respect to Medicare, but a lot of people are asking about pre-existing conditions and if that would actually deter private, as well as public, insurances for them.

Monica: So, are we talking about health insurance or other types of insurance?

Lizette: Health insurance.

Monica: Okay; so, under the Patient Protection and Affordable Care Act, otherwise known as the ACA or Obamacare (it's all the same thing), it was a law signed in 2010 and that said that starting January 1, 2014, insurance companies can no longer deny selling somebody a policy or covering services related to a pre-existing condition. Insurance companies also can't charge more if somebody has a pre-existing condition. So, the one place where that doesn't exist in health insurance is the Medigap plans or

the supplemental plans I was just talking about, but for other types of insurance—so, private insurance that’s purchased directly from a health insurance company, insurance you get through your employer, or Advantage plans, they cannot discriminate based on a pre-existing condition under the Affordable Care Act.

Alicia: Thank you. Are there any updates on if Medicare can or will be allowed to negotiate prices with the pharmaceutical companies?

Monica: So as of right now, they cannot, but there’s several proposals that are floating out there in Congress to maybe pass some legislation to allow them to do that. And then, several of the presidential candidates, currently campaigning, are also discussing that as an option.

Alicia: As a cancer rights attorney, what conversations are you guys having?

Monica: I mean, to be perfectly honest, it’s not something that we’re totally involved in. We are really focused on teaching people the systems that we have right now so that they can navigate them, but then also encouraging people to engage in advocacy. So, if this is something that they care about, they should absolutely be talking to their elected officials about it and how it’s impacting actual real-life Americans.

Alicia: Absolutely. Advocacy is so important because, as our listeners know, LLS exists to find cures and insure access to treatments for blood cancer patients. In order to advance this mission, our LLS Office of Public Policy, supports a policy agenda aimed at accelerating the development of new treatments for cancer and breaking down the barriers to care that patients often encounter. So, to your point, advocacy is so important and there is so much we can do to get involved and to share our voices so others hear our voice and see that we’re really doing our best to try to get the best treatment for cancer patients.

Lizette: Sure; and if anybody wants to join our advocacy efforts, you can just go to lls.org/advocacy and all of our take-action topics are right there for you. We’re there to improve cancer care for pediatric patients, promote insurance access for cancer patients improving medication access, and making the healthcare system sustainable. So, we do have many things to offer in your local, as well as federal, agencies.

Alicia: Along the lines of advocacy, we received a question that said, “what can be done to make employers more aware of employees with cancer?”

Monica: The employment arena is a little bit tricky when we start talking about cancer because, certainly, there are legal rights that exist to protect both employers and employees, but we also want people to know that they have some choices around disclosure. And it comes as a surprise to a lot of people that they don’t necessarily have to tell their employer or their potential employer, if they are in the job search

process, that they've had a cancer diagnosis. A lot of times we hear people say, "oh, I wish I would have known. I would have made different choices." But even if you are trying to access legal protections and rights, you may be able to do it in way where you protect your privacy and the specifics around your diagnosis if that's important to you. But then I would also say that people shouldn't feel like they don't have the right to exercise those benefits if they want to keep it private. I know that a lot of employers are actually much more generous than what the law requires so people should be checking employee handbooks and manuals, and policy and procedure documents, to see what the employer lays out, but then also exploring what the employer already has.

Alicia: Right; and discrimination can happen during the hiring process when employees (employers) overlook qualified candidates because of the fear of the impact of cancer on their ability to do their job. And I think it is so important, like you said, for patients to know their rights, especially if they are in the position to work, knowing that they don't have to disclose information regarding a diagnosis. You know, whether it be an interview or even after. So, I think, like you said, I think it is very important to check the employee handbook, check the conversations happening, the laws and rights, surrounding cancer patients when it comes to employment and what they can do once they are either looking for a job or have received that job.

Monica: Absolutely. I mean, unfortunately, we have statistics now that show individuals who have disclosed in the hiring process are less likely to get hired. So, that is an unfortunate reality. I will also say, for anyone who is interested in learning more about what their rights are around disclosure and privacy and accessing these benefits, at trinecancer.org under resources by topic, we have a whole page on employment rights and we have several things where people can read a little bit more and get some more details.

Lizette: That's great to know. And if somebody already has a position and they don't want to disclose to their immediate manager, do they have the option to disclose to their H.R. office without their immediate manager not knowing?

Monica: So, that is a possibility. We have to remember, though, that not everybody has a formalized H.R. department. They are lots of different ways that employment settings are constructed. If somebody is trying to do something like ask for medical leave or ask for what's called a reasonable accommodation, then they may have to disclose some information about their medical condition so that the employer knows they're eligible for that benefit. Many employers will lay out a process of how to go about asking for those things and, if that process says "go to your H.R. department", then you can do that. Now, requests for things like medical leave and reasonable accommodations are supposed to be kept confidential so the details can't be shared with a supervisor. But, certainly, if, you know, somebody's getting a reasonable accommodation let's say of taking every Friday off for treatment, then it stands to

reason the direct supervisor needs to be given that information, but not the details as to why they are getting the reasonable accommodation.

Lizette: Sure; okay.

Alicia: And you mention under trinecancer.org, Monica, I just want to emphasize to the listeners how—I mean I attended a number of the conferences that you guys have and one of the topics discussed is about employment issues, and working through treatment, and taking time off, disability insurance, returning to work; and it is such a great fountain of information for people who may live in the community and of places where there might not be a major center where they can't get this type of information on a regular basis. So, I just want to really encourage listeners to visit trinecancer.org/conferences and see, you know, the schedule of their upcoming conferences 'cause you can really learn such a great deal about so many different things relating to cancer and navigating throughout insurance and finances, and all of those things.

Monica: Well; thank you so much for that plug and we certainly appreciate LLS's support of those events.

Alicia: No problem. The next question that we have -- it was interesting because this was the only question that we had about it; and I actually never really thought about this question. It was about creditors and it said, "if any, what type of help can you suggest to help avoid being hassled by creditors regarding bills pertaining to cancer?" And the person said that it seems as if mailing them their explanation of their disease is not enough so they wanted to know what else can be done to keep them at bay?

Monica: So, we actually hear this a lot, unfortunately, because the reality is that sometimes bills do get sent to collection agencies. We like to help people avoid that from happening, and there's a whole host of ways to do that including negotiating with providers before things are sent to collection, but there are a host of state and federal laws that have been passed to curb the abusive practices that were happening with debt collectors in the past; and so—I mean, there's tons of them, but for example, you know, debt collectors can't contact you between certain hours in the evening. They can't contact you repeatedly at work if you have told the debt collector that you are working with an attorney or a debt--credit counseling agency, they can't continue to contact you. They're supposed to contact the attorney directly. So, there really are some things to protect consumers in these circumstances.

Alicia: That's great to hear.

Lizette: Yeah; I didn't know that. Very interesting. I know that we've gotten a few questions about people who—who do have, employment-based insurance and, even one person was saying, "I worry about the cost of treatment more than the treatment

itself.” And they are saying that, you know, what happens when the patient will be losing their employer-sponsored healthcare coverage? They’re trying to figure out what they are going to do next and another person does bring into light that they won’t be able to afford—usually when you lose your employment-based insurance, you can pay for your insurance out-of-pocket for a while and they won’t be able to afford that because, usually, that’s at a higher rate. So, people are asking, “is there anything they can do or anything they can take into consideration if they are losing their insurance through their employer?”

Monica: Sure. Over 50% of Americans get their health insurance from their employer so this a very common question that comes up. There is a federal law called COBRA that allows individuals who work for employers with 20 or more employees to keep the exact same health insurance policy that they had when they were working, even though they are no longer able to work. And there’s a couple of different qualifying events. If someone is leaving their job for treatment and recovery, they would generally be able to elect COBRA coverage for up to 18 months. Now, the hard part about COBRA is, as you alluded to, it’s expensive because, typically, when you are working, the employer pays a portion of your premium and you pay a portion of your premium. Well, with COBRA, now you’re responsible for 100% of that premium plus sometimes a 2% administrative fee. And so, many of us don’t appreciate how much our employers pay for health insurance until we are writing that check ourselves.

If someone works for a smaller business that doesn’t have 20 or more employees, they may be covered under a state COBRA law and the details vary state to state. And, if you are interested in that, at tragecancer.org/statelaws, we have charts of state laws that give some more details there. But what’s great news is since the Affordable Care Act, we now have more options than ever if we are losing our employer-sponsored insurance. So, COBRA may still be a very important option for people, and the reason is, is that if somebody has already met their deductible and their out-of-pocket maximum for the year, then paying those higher monthly premiums and knowing that’s all you are going to pay for the year, may actually make more financial sense than finding a new plan and starting over at zero and trying to meet that deductible and that out-of-pocket maximum, but, you have to do the math, as we talked about earlier. So, people are able to purchase a new plan in a state health insurance marketplace that was created under the Affordable Care Act and they can look at their options at healthcare.gov. But, again, they are going to need to do the math and make sure that their providers, their prescription drugs, their facilities are all covered under that new plan. So, that’s the second option.

So, COBRA may be an option. Buying a new plan in the marketplace may be an option. Perhaps, they can go on a spouse’s plan at work. Or, if they are under the age of 26, they may be able to rejoin their parent’s plan if their parents have an employer-sponsored plan; and then, finally, they may be eligible for Medicare or Medicaid based on their change in circumstances.

Now, the other thing about it that sort of is a little known secret is some states have a program where they—if somebody is eligible for Medicaid and also eligible for COBRA coverage, the state may actually pay their private COBRA premium for them, but you have to apply for that if you are eligible.

Lizette: Oh; I didn't know that. It's good to know.

Monica: Yeah—it's a well-kept secret.

Lizette: Well, I'm sure you uncovered that secret well on your—on your web page.

Alicia: And that is the purpose of this podcast is to make sure we find out what those secrets are and get them to the people that need them.

Monica: I also just want to say that if someone is sitting there listening to this and thinking, "Wow, I really would like to hear all of that again". At trialecancer.org, we actually have a little animated video. I think it's about 6 minutes long and walks people through the analysis of how to pick a health insurance plan and actually how to do the math that I know that I've said a couple of times today. So, it might be worthwhile to take a look at that if someone's facing this decision of what do I do? COBRA or a new plan. You know, what are my options?

Lizette: And I think that is really important because it really does bring to light all the things you have to take into consideration because I know that most people look at all these plans and you pretty much look at how much is it going to cost you per month or per year but as you've said before to us which I think everybody really needs to know, is that you have to take into consideration your personal needs when choosing a plan because the one that looks like it's going to be the cheapest in the long run may actually be the one that costs the most for you. So, I think it's really important.

Monica: That is exactly right. So, most people, because we are not given any other information, will pick a plan based on that cheapest monthly premium, but they don't always look at, well, what's the deductible and what's the out-of-pocket maximum? And for most individuals who are in the midst of cancer treatment, they are going to meet that out-of-pocket maximum. And so people really need to be doing the math where they multiply the monthly premium times 12 and then they add the out-of-pocket maximum; and that's the most they are going to pay for the year, assuming that they see in-network providers. So, when you do that math, sometimes that plan that's more expensive monthly ends up being cheaper at the end of the year.

We also see people not looking at that deductible. So, you could have a plan that's cheaper by the end of the year, but has a \$6,000 deductible, which means that you have to write a \$6,000 check before the plan even starts picking up their share of the costs. And for most of us, we don't have \$6,000 laying around to just write that

check. So, again, something with a higher monthly premium, but a low deductible spreads out what you're paying throughout the year instead of having to come out with that big lump sum. And these are things that, again, none of us are ever taught how to make these choices.

Lizette: Right; and it's important, especially if you have a cancer diagnosis, where you know that you're going to, you know, spend a lot of money in the beginning of treatment and you are going to reach that deductible quite quickly.

Monica: Right. I mean, some people will reach their deductible and their out-of-pocket maximum in January based on their treatment.

Lizette: Wow!

Alicia: So, our next question is, "what do I do if the time period to stay on my employer's insurance through COBRA runs out?"

Monica: So, now you are at another point where you have to start making these decisions as to what's next. So, when your COBRA runs out, you'll be eligible for what's called a "special enrollment period" to buy a new plan in the marketplace. So, you have 60 days from the date that your COBRA is ending to make those choices. And, again, maybe you're eligible for a spouse's plan, or a parent's plan depending on your age. Maybe now you're eligible for Medicare or Medicaid. Or maybe you are at the point now where you are looking for a new job and that new job has employer-sponsored insurance.

Alicia: This question that was submitted said, "is there other insurance, other than Medicaid or Medicare, once your job insurance stops?" The COBRA plan is too much for people that have no income coming in.

Monica: For that person, I would suggest looking at what their options are in the marketplace because, in the health insurance marketplaces set up by the Affordable Care Act, there is also financial assistance and that financial assistance is based on household size and income. And there's some staggering statistics coming out recently. I think something like half of the individuals who are uninsured in this country would be eligible for a bronze plan for free...

Lizette: Really!

Monica: ...but, they just don't know about the marketplace and the financial assistance so they are uninsured. So, I would definitely recommend for that person to take a look at what's available to you in the marketplace and what sort of financial assistance you might be eligible for. I would also say, if they are eligible for Medicaid, which is based on income, in their state, their State may have this program that I

referred to, called the HIPPA program, where the state may pay their private COBRA premiums instead of paying for all of their care through Medicaid.

Alicia: Wow! Thank you for that. Now, shifting gears a little bit to appealing health insurance. So, many patients have a built-in tendency to take “no” for an answer when it comes to their health insurance. Can you explain a situation in which an appeal was something that was encouraged and ended up changing the outcome for a patient?

Monica: Appeals are another one of those secrets in this situation. Many patients after a cancer diagnosis at some point through their treatment experience, will get a denial from their health insurance company; and we really urge people not to take “no” for an answer and to utilize the appeals process. And there’s generally 2 different levels of appeal. There’s an internal appeal that’s done within your own health insurance company where you get to go back and present some more information. And then there’s an external appeal; also referred to as independent medical review or external medical review; and some states had this previously, but under the Affordable Care Act, every state is now required to have an external medical review process. Usually, it’s done through the Department of Insurance in that state and it is an independent body that gets to look at all the evidence and then make a decision should the insurance company have paid or not. We have some statistics that upwards of sixty percent of all appeals are decided in favor of the patient. So, sixty percent of the time the insurance company gets told NO, you were supposed to pay.

Lizette: Wow!

Alicia: That is a great stat.

Monica: But people don’t know. People don’t know that this exists. It’s one more burden. It’s one more thing that gets placed on the plate of the patient and the caregivers to have to deal with which is inherently unfair, in my opinion, but when you think about this problem of financial toxicity and how challenging finances become after a cancer diagnosis, appealing is just one more way where we can start to address this and deal with the financial impact. But people have to know what it is and how to deal with it.

Lizette: Exactly. Many people don’t know about the appeal process and, you know, I’m glad that we’re letting people know. Is it difficult to appeal? Can somebody do it on their own or would they need assistance?

Monica: So, generally speaking, we recommend that individuals who are diagnosed, and caregivers, work with the healthcare team because, depending on what the reason for the denial was, you’re probably going to need some evidence and some supporting documentation for your appeal. So, for example, if the claim is denied because it was

experimental or investigational—so, let's say it was an off-label drug use or a clinical trial, there's a reason why that healthcare team made those treatment decisions. So, the patient needs to be collecting that information from the healthcare team to submit it with their appeal. We have a quick guide that we just released earlier this month on our web site. It is totally free to download where we walk through the steps of how to do an appeal and the types of documentation that can be really helpful.

Alicia: That is such a helpful resource. And, like you said, it is so unfair because someone, again, is given a diagnosis and then has to learn about the--their diagnosis—has to then, kind of, get things in order in regards to treatment and caregiving and all of the stuff. And if it's something, like you said, a stat so high as 60% in favor of the patient, it's then having to add something else to the list that the person then now has to do, which the they shouldn't have to do.

Monica: Definitely

Alicia: So, I think it is so great that you offer that guide for people to see it in front of them and not feel as if they are, kind of, chasing their tail, but something is out there to help them. So, thank you so much.

Now, shifting gears again to financial aid. Someone said that it seems like there are various resources for financial aid for the young and the old, but there doesn't seem to be much help for those fall in between. Do you see this as a common concern and, also, what financial assistance do you know of can be provided for caregivers, who may live elsewhere, but may need to travel to help the patient?

Monica: The topic of financial aid is such a tricky one. There are some fantastic financial assistance resources out there. Certainly, LLS provides some great ones, but the reality is that there just isn't enough to go around to solve everybody's every problem. Certainly, when we talk about governmental programs, it usually is income-based or age-based, but there are some fantastic private foundations and resources out there. At cancerfinances.org, we have culled some cancer financial resources and categorized them. Generally speaking, when I talk to people who are looking for financial assistance resources, I urge them to be as creative as possible and to think outside the box. It's really easy to get tunnel vision when we are dealing with these crises. For example, you know, I need help paying for my prescription drugs. That's the thing I can't afford. But, as I sort of talk with people, I try to get them to think about, "well, what do you have money set aside for?" Maybe you have money set aside for utilities, pay your utility payments or gas bill. Well, maybe we can get you utility assistance so that you can shift those funds to pay for your prescription drugs. And that's, of course, just one example. But it's hard, and it takes a lot of leg work, and a lot of time, and a lot of effort; and, you know, you may put out 50 applications for financial assistance and only get one thing back. So, it's certainly not a fool-proof system, but when we talk about finances and how to reduce the financial barrier, we

want people to be thinking about it in the most holistic and wide way possible. And, the number one way to do that is to make sure that people have adequate health insurance so that their out-of-pocket costs are as low as possible, but then also to utilize some of these other programs that I have been talking about.

Lizette: And I know that over the years, we've been wondering about any changes with any of the public insurances. You know, I've been waiting to see if the folks under the age of 26 that could be on their parent's insurance, if that is going to change any time soon. Any changes that we should know about for our cancer constituents?

Monica: Well, it is really interesting that you bring that up because there are constantly changes occurring. One of the things about the Affordable Care Act is that it's a huge law and there are so many moving pieces to it; and there's state regulations, and federal regulations, and court cases. So, there have been lots of changes since it was first signed in 2010. One of the biggest changes that we continue to see is which states have decided to expand their Medicaid programs. So, originally, in Medicaid, someone had to have a low income and a low asset level, which is, like, bank accounts or retirement accounts and they had to fall into another category. So, typically, people who were diagnosed with cancer would fall into what is called the "age, blind and disabled program"—the worst name ever for a program, but that's what it is called.

Alicia: That is definitely the worst name for a program.

Monica: Yes; it is really terrible.

Alicia: Oh my gosh.

Monica: Yeah; and it's a really high standard to get into that. So, it was leaving people who couldn't meet that high standard of disability, or people who maybe had a retirement account where they would literally have to spend it all in order to be eligible for Medicaid. So, the Affordable Care Act said, "let's create a new category of people who are going to be eligible for Medicaid and it's just going to be based on income." So, if you have a low income, then you are going to be eligible and it was supposed to happen across the country. Well, the Supreme Court got their hands on the Affordable Care Act and, essentially, made that voluntary for states. And so, over the last handful of years, we've seen states decide to expand their Medicaid, or not decide, or go back and this is the thing that changes most frequently. And we actually have a chart on our website where we try to keep track of where states are, but we also, as elections happen and states get new governors and new legislators, that changes state to state. So, that's a big thing that people should be keeping their eye on.

And then the other thing is there's currently a court case working its way through the courts that could have a huge impact on the cancer community; and that case is Texas

v. U.S. And in that case, a Texas judge has ruled the Affordable Care Act unconstitutional.

Alicia: Wow!

Monica: Yeah; it's currently sitting at the appeals courts and I'll spare you all the super intricate legal analysis about what's going on, but essentially, we could see the Affordable Care Act end up back at the Supreme courts and there is a potential for the law to be ruled unconstitutional, where we would then go back to the days of people being denied purchasing health insurance because of their pre-existing condition, where young adults couldn't stay on their parent's plan unless there was a state law that said otherwise, where all of these consumer protections that we've now become used to in the last five years are eliminated, essentially, in the stroke of a pen.

Alicia: That is so terrifying.

Monica: It really is. It really is and we are trying to keep track of what's happening. And, certainly, as things happen and if we get a decision, we'll be posting that on our blog, but we really think that, at least in my experience and my everyday life, the average American has no idea that this is happening in the court system and it's pretty scary.

Alicia: Wow! And I know you said you didn't want to get into the intricacies of this, but what are—I'm curious to know how is it being labeled as unconstitutional?

Monica: Sure.

Alicia: Sorry, listeners.

Monica: So, in 2017, Congress passed a resolution where they reduced the penalty for not having insurance to zero dollars. And so, when that happened, two gentlemen in Texas, plus the Texas Attorney General, plus several other Republican state's attorneys generals filed suit in Texas saying that now that that penalty is zero, the Affordable Care Act should be ruled unconstitutional because, then, Congress didn't have the power to write this law.

Lizette: Really, a zero penalty means no penalty, which means that you don't actually have to purchase it.

Monica: Yes; it has to do with the constitutional powers of how Congress is allowed to write laws and so there's, you know, there's some constitutional arguments here, but what's really fascinating about this is the Department of Justice is the federal agency that is supposed to step into court and defend federal laws. Well, when this

case was brought, the Department of Justice said, “we’re not coming to Court to defend the law.”

Alicia: Wow!

Monica: So then, you had--yeah, the California Attorney General, with a handful of other attorney generals, ask the Court, “can we step in to defend the law?” So, we will take the place of the Department of Justice.

Lizette: Wow

Monica: And the Court said, “yes”. So, it’s a very interesting legal situation that we are in. This is very uncommon. When we got the new Congress, after the election, the House of Representatives also passed a resolution saying, “we would also like to join the attorney’s generals that are defending the Affordable Care Act and the Court said, “okay”. Well now that we are at the appeals court, there is a question of if it was appropriate for the Texas court to allow the states attorneys generals and the House of Representatives to defend the law; if they had standing to defend the law and to then, therefore, appeal the law. And so, that’s where we are sitting right now. We’re waiting to hear from the Fifth Circuit courts if that was, in fact, permissible. So, if the Court comes back and says if those groups didn’t have standing, then there’s two things that could happen; one the Texas judge’s ruling stands and the Affordable Care Act is unconstitutional; or the Fifth Circuit could come back and say, “start over from the beginning” and rehear the case.

Really every American should want to know because it is going to impact all of us because there is, sort of, this misconception that the Affordable Care Act only matters if you don’t have insurance and that’s just not the case. It has touched almost every aspect of our healthcare system. Hospitals have a vested interest in this. Insurance companies have a vested interest. It’s provided us protection as consumers of healthcare even if you get your insurance through an employer. So, frankly, in my opinion, this is something all of us should be caring about, but again, it is so technical and very theoretical at this point that I think a lot of people just don’t know what’s going on.

Lizette: It’s definitely not on prime time.

Monica: It is not; and that is a problem, as my long-winded explanation demonstrates, is that when the news channels can’t explain the complexities of all of this in one of their, you know, 2-minute news segments. So, even if they do talk about it, it generally isn’t the whole story.

Lizette: Right. I think one of the biggest things is that people who have insurance already, that do not have insurance through the Affordable Care Act, so mostly

through private insurance, through their employer, may not think that any kind of decision with the Affordable Care Act has anything to do with them—that there is no implications because they are already paying through their employer and they feel that it's just going to impact people that are on the Affordable Care Act; and you just said that it would impact all of us, correct?

Monica: Absolutely. This is not just about people who receive Medicaid or people who purchase a plan through the marketplace. The consumer protection, for example, one of the consumer protections that the Affordable Care Act provided was that it said that insurance companies can't place annual or lifetime limits on the dollar amounts that they are going to pay out for somebody's care. That impacts you if you have employer-sponsored insurance. We would go back to the days where insurance companies could place limits. And we saw limits like \$75,000 a year and, once you hit your cost-of-care being more than \$75,000, they just stopped paying.

When you start to think about cancer care, you can reach those limits very quickly. So, that's just one example of a protection that the Affordable Care Act gave us that would go away.

Lizette: That's very important for us to know. Really, for our cancer constituents to really understand that because with the new cancer medications, the new developments, the new treatments—there are some new treatments that are half a million dollars, so that's very important for our constituents to know.

Monica: And remember, we've had lots of questions about, "well, what happens if I stop working due to my cancer? What am I going to do for insurance?" Well, before the Affordable Care Act, really, the only option was COBRA.

And COBRA doesn't last forever. And again, it's still a good option for some people in some circumstances, but it was the only option. It was not that long ago where we were in a time where you got health insurance and you held on to it for dear life because you had no idea if you were going to be able to get another plan once you had a pre-existing condition. And a pre-existing condition doesn't have to be cancer. It could be high blood pressure, or diabetes, or acne, or pregnancy, or all things that were considered pre-existing conditions where people could be denied or charged more prior to the Affordable Care Act. So, it's funny to me because, in the last 5 years since we've had these protections, I think that we've all gotten very comfortable in this new world we live in, but it was not that long ago that things were very, very different. So, you know, for us to go back to that world is quite terrifying.

Alicia: Absolutely. Monica, is there any common question or anything that you feel that we didn't mention or that you think is worth mentioning for our listeners?

Monica: I think we covered most of it.



Alicia: Monica, along with all of the things that we mentioned today, just shows how complex and technical this world is. So, we cannot thank you enough for all the work you are doing for cancer patients and their caregivers.

Monica: Well, right back at you. We are delighted to have LLS as a partner.

Alicia: For those listening who may have a question pertaining to any of the things that we discussed today or have questions that may have not been answered, please visit www.lls.org/support for a list of all of our resources. You can also call an information specialist at 1-800-955-4572 Monday to Friday, 9 a.m. to 9 p.m. Eastern Time. Please also visit www.triagecancer.org for educational materials and resources on practical and legal issues.

The links that we mentioned on today's episode will be listed below this episode so please also comment below with how you liked this episode as well. So, thank you so much for listening.

Lizette: Thank you.