

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'You Aren't Alone: Navigating The Financial Impact of Cancer'

Description:

Dealing with cancer extends beyond physical health, often bringing financial challenges that can overwhelm patients and their loved ones.

In this episode, we offer a beacon of support as we speak to Monica Bryant, Esq., a cancer rights attorney and Co-founder/Chief Operating Officer of Triage Cancer. She reviews the financial hurdles that may arise during treatment and provides practical strategies to help with economic hardships. She also highlights a wealth of resources designed to aid patients, covering everything from financial grants to transportation, Social Security benefits and navigating the complex world of health insurance.

Transcript:

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

Holly: And I'm Holly. Thank you so much for joining us on this episode.

Elissa: Today, we will be speaking to Monica Bryant, a cancer rights attorney, speaker, and author dedicated to improving access to quality information on health care issues. She is the Co-founder and Chief Operating Officer for Triage Cancer, a national nonprofit organization that provides education on practical and legal issues that may impact individuals diagnosed with cancer as well as their caregivers.

Throughout her career, Monica has provided nearly 1,000 educational seminars for cancer patients, caregivers, lawyers, advocates, healthcare professionals, elected officials, and the general public; and we are thankful to Monica and Triage Cancer for educating and supporting our blood cancer patients over the years as Monica has been featured in many LLS programs. And we are happy to have her speak with us today to discuss the financial aspects of cancer. Welcome, Monica.

Monica Fawzy Bryant, Esq.: Thank you so much for having us.

Elissa: So, our episode today is on cancer and finances. We know that after a cancer diagnosis, patients and their families can be really impacted financially. What are some common ways someone may be impacted?

Monica: The financial impact of a cancer diagnosis is certainly something that we spend a lot of time talking about. I would say that sometimes the conversation is around the cost of care, but that really doesn't show the full picture of the financial impact that both the individual that's been diagnosed faces but also the caregiver and the sort of larger family unit.

We actually believe that there are multiple contributing factors to this financial burden or hardship and that what we do at Triage Cancer in educating people about these factors is going to help people avoid the financial burden. And from our perspective, the most significant contributing factor is somebody's health insurance status.

Now, that could mean not having health insurance at all; but really what we see to be the case more often is that someone that doesn't have the right health insurance for them or they don't know how to use the health insurance that they have.

Our healthcare system is incredibly complicated, and we're never really taught how to understand health insurance or how to use it, and so we spend a lot of time talking about that at Triage Cancer.

And the second most significant contributing factor to financial burden is someone's employment changes.

So, whether someone has to take time off from work, whether they can no longer do the job they were doing before, whether now because of their experience they maybe want to change careers. And if they do have to take time off, how do they replace that lost income? And so, there are laws and programs that can help people both stay

at work and work through treatment and also take time off and replace lost income if needed.

Holly: So, let's talk about that biggest impact that you mentioned, insurance. Even though a patient may have insurance, what kind of out-of-pocket costs may there be?

Monica: So, one of the reasons why we say health insurance is so complicated is that you have to basically learn a new language in order to be able to understand it. There are all these words that get tossed around that are very rarely defined for people. And what I mean is things like your premium, which is what you have to pay every month just to have health insurance, and you're going to pay that every single month whether you go to the doctor or not.

Then there's the deductible, which is a fixed dollar amount that we have to pay each year before health insurance even kicks in; and that could depend on the plan. So, someone could have a \$5 deductible; they could have a \$5,000 deductible.

And then there are other costs that we incur when we actually go and see the doctor or use our health insurance; and once someone's met their deductible, then the coinsurance kicks in, and this is always going to be a percentage. And so, someone may have an 80/20 plan or a 70/30 plan. Once someone's met the deductible, then the health insurance kicks in; and they're going to pick up, let's say, 80%. And then the person's going to be responsible for 20%.

Then, most policies have an additional payment called a copayment. And that, again, it's going to be a fixed dollar amount that you have to pay every time you get care. So, this is going to depend both on the policy but also on the service. So maybe someone's got a \$20 copayment to go and see their doctor but a \$30 copayment to see a specialist or a \$250 copayment if they go to the ER. So, those are the out-of-pocket costs that someone's going to experience, and those could be both for medical care, like seeing the doctor, also for prescription drugs.

But the most important thing that every one of us needs to know about our health insurance is if there's an out-of-pocket maximum and what is it? Because the out-of-pocket maximum is the most we're going to pay for our care during the year. Once you've met your out-of-pocket maximum, as long as you're going to in-network providers, insurance is going to pick up 100% of your costs for the rest of the year.

Elissa: So, really, it's also choosing an insurance that, one, you'd be able to afford the deductible; but then two, you'd be able to do something with the out-of-pocket maximum for the year.

So, say, a lot of our patients end up having a hospital stay, right, and so they had coinsurance. We're just going to put out a round number of \$100,000 and they had 20%, so it's \$20,000 which sounds just outrageous and hard to be able to afford. But then they have an out-of-pocket maximum of \$10,000. So, is that all they would pay for the year is that \$10,000 and then it's 100% covered for the rest of the year?

Monica: That's right. And now they still have to pay their monthly premiums.

Elissa: Right.

Monica: So, we're always going to have to pay those monthly premiums, but you're absolutely correct. So, instead of that \$20,000 bill, they're only going to be responsible for up to \$10,000 of it. And any other care they get for the rest of the year, assuming that they go to in-network providers, is going to be covered at 100%.

Elissa: That's great. Now, what about patients who may have lost insurance if they haven't been able to work after a diagnosis? You briefly brought up it being tied to employment. So, what happens then?

Monica: About 50% of us in this country get our insurance through an employer, so it's a really common question that we get, "What do I do now?" There are a number of options that are going to depend on a variety of factors. It's always tricky talking about these things in general because when someone comes to us and asks us a

question like that, typically our response is us asking them about five more questions because in order to understand what their options are, we need to understand things like how big was the employer? What state do you live in? How old are you? What other options do you have because all of those answers are going to help us identify what potential options someone might have.

So, for example, if someone works for an employer with more than 20 employees, they might have access to something called COBRA, which is a law that allows individuals to keep their employer-sponsored coverage. So, it's the exact same plan. Everything with respect to how much someone's paid towards their deductible or their out-of-pocket maximum, all that continues.

The downside is that the employee is now responsible for 100% of the monthly premiums. And we often say we don't appreciate how much our employers are typically paying towards our health insurance until we have to write that check ourselves. So, COBRA can sometimes be unaffordable for that monthly premium.

So, then we would look to see, is there another group plan you could go on, like a spouse's plan or if someone's under the age of 26, they could go on their parent's plan potentially. Even if they're married or even if they have their own children, it's just based on age.

Maybe they could access picking up a new plan through the State Health Insurance Marketplace, and those are plans sold by private insurance companies. It's private coverage. It's just sold through the marketplace that the government created.

Elissa: Right. And they can do that at any time after losing their insurance?

Monica: Not any time. There's going to be something called a special enrollment period, and so someone has 60 days after the loss of coverage to pick up a new plan. And interestingly enough, that coincides with the 60 days someone has to decide if they want to elect COBRA or not, if they're eligible. So, they have about two months



to make those decisions. Interestingly enough, the marketplace has made some changes where people can actually now enroll if they're expecting to lose coverage in the next 60 days.

And that's a really helpful change because people don't have to wait until they lose coverage and then potentially face a gap in coverage which, as you know, could be really detrimental if someone is in the middle of treatment.

Elissa: Right. If a patient did lose their employment, and so they weren't working and then they'd started cancer treatment, would they be eligible for Medicaid in most states?

Monica: Really great question. So, Medicaid, for those of you that are listening and might not know, is a health insurance program run by the federal government; but it's a federal-state partnership, so there are definitely differences among the different states.

In 39 states and DC (District of Columbia), if someone loses their job and has an income less than 138% of the federal poverty level, which for this year is about \$20,000, then they could access Medicaid. And that change has been around for about ten years now. Again, it's state to state. There's 11 states that have not expanded their Medicaid program. And in those states, there's additional requirements. So, you not only have to have a low income, you have to have a low asset level, which means things like bank accounts or savings accounts, or retirement accounts, and you have to have a disability that meets a pretty high standard. So, it's not impossible, but it is harder in those states that haven't expanded.

Elissa: Okay. Now, digging a little bit more into insurance coverage, we know that some treatments occasionally may be denied by the insurance company. These can be clinical trials or experimental drugs, or it could just be a standard treatment that gets denied.



For example, I was in treatment for acute myeloid leukemia, and they denied my very last Neulasta® shot, which is needed after chemo; and it was my fourth chemo. And they had denied the shot afterwards, and my treatment team spent four hours trying to work with the insurance companies, and they couldn't get it. And so, the alternative was to do a shot called Neupogen®, which I'd then have to go into the hospital every day for ten days versus a single shot. And I ended up having to eventually call the insurance company, and then it was approved. And it was just, very, very frustrating to get something denied that seemed to be a very standard procedure. So, what can a patient do then if treatment is denied?

Monica: Well, first, I will say I'm sorry that you experienced that; and I wish I could say I was surprised. But unfortunately, denials are incredibly common; and so, I'm delighted to hear that your healthcare team went to bat for you and really worked on your behalf for that.

If someone receives a denial, they absolutely should not take no for an answer. In most types of health insurance, there's going to be an opportunity to appeal that denial; and there's going to be at least two levels of appeal. So, when we're talking about like individual- and employer-sponsored coverage, the first level of appeal is internal where you're going back to your insurance company and saying, "Please reconsider. Here's why." And it sounds like that's what you had to do.

But even if someone loses or is still denied at the internal appeal stage, they have the right to go get an external appeal, which is an independent entity that's decided in your state that is going to look at the plan documents, it's going to look at the medical information, and it's going to decide whether or not this service, whatever it is, is medically necessary. And that decision is binding on both the insurance company and the patient.

This is, to your point, incredibly frustrating; and we're sort of adding more to an already too full plate when we think about these are people who aren't feeling well.

They're in the middle of treatment. They've got a ton of other things going on, and now we're saying, "Go up against an insurance company. Go through all of these steps." However, the reason we say it is worth doing is because we know that somewhere between 40 and 60% of all external appeals are decided in favor of the patient.

Elissa: Oh, that's great.

Monica: So, roughly half the time when the insurance company is saying, "No, we're not going to cover that," when an independent entity looks at it, they're getting it wrong.

The concerning part for us as advocates is we know that people aren't appealing. And we have all sorts of data to back that up. One piece of information is that, when just looking at the marketplace denials, there were 48 million claims denied in 2021; 48 million claims were denied. 99.9% of them were never appealed.

Elissa: Wow!

Monica: Yet, we know when people appeal to the external-

Elissa: Yes.

Monica: Right, like they're getting it wrong half the time. So, when we talk about financial burden and access to care and quality of life, right, this appeals process is an incredibly valuable component of addressing those issues.

Elissa: Now, I want to make sure that our listeners will understand how to do this. Do you have information on the Triage Cancer website on how to start an appeal?

Monica: We do. So, on *TriageCancer.org*, we have a whole section on our health insurance page about how to appeal; and we have that information in a variety of formats. So, we have, a quick guide that outlines the steps to take. We have an

appeals tracking form, which is something that someone can download. All of our resources are free to download or to read online.

And the tracking form is really useful, both as a way to just stay organized because, as you indicated, there are lots of conversations that happen with providers and insurance companies; but it's also a really helpful tool because it can sometimes trigger a reminder to ask the question.

So, for example, I'm on the phone with the insurance company; and I have my tracker form in front of me; and there's a box that says, "Expected date of response." That's going to help trigger me to say, "And when should I expect to hear back from you" or "When should I expect to get that piece of mail, so that I know next steps?" So, that's available on the website. We have a recorded webinar that does a deep dive into appealing for a variety of types of insurance because it does get a little different if we're talking about Medicaid or various parts of Medicare. But in all of those types of insurance, there is the ability to appeal.

Elissa: So, we've heard about some patients getting approval with compassionate use for a drug that may not be approved for the indication. What happens there?

Monica: So, that's an FDA approval process, and it's actually quite useful. As you know, the FDA approves drugs for certain indications; and then research continues on those drugs, and they might find that actually this drug isn't just helpful for X cancer. It's also helpful for Y cancer, but the FDA hasn't necessarily approved it for Y cancer. So, there is a process to actually go to the FDA and say, "Will you give approval for me to get this drug?"

Now the pharmaceutical companies are also involved in that because they have to okay use of this drug as well. But it's a very successful process.

Elissa: Good.

Holly: We know that patients and caregivers may lose their jobs or be unable to work during treatment. What is the financial impact with that?

Monica: Well, certainly the financial impact is going to be the same for anybody who loses their job. I think the message I would want to leave people with are, there are programs and laws and benefits that could actually keep someone at work. And what we find is that patients are often up against a lot of assumptions. So, it's their own assumption that they cannot work, and there's nothing that is available to help them. It's perhaps their employer's assumption. "Well, now you've been diagnosed with cancer, so, you can't work." And oftentimes it's the healthcare provider's assumptions of, "My patient can't work or wouldn't want to work, so just go out on disability."

When in reality someone may need to work, or someone may want to work. Many of us do our jobs because we enjoy them, and they bring purpose and all sorts of other things besides just that financial component. So, I think it's important that we don't start with the premise of "You can't work, and there's nothing that can help you." Certainly, that's going to be true for some people, so I'm not dismissing that. But for the people that maybe can work, but they just need a little extra support, there are things that are available like reasonable accommodations under the ADA. And so reasonable accommodations is really any change, and so it could be things like changing your work location. So, if someone has to have infusions for eight hours a day but they have a computer-based job, maybe they can work from the infusion suite. Maybe it's about extra breaks, or shifts in schedule, or changes in policies. And so, there are lots of things that we know that individuals who've been diagnosed with cancer get at work as reasonable accommodations. And those are the things that help them stay at work, which, of course, helps maintain income and oftentimes health insurance.

But if someone does need to take time off, then it's about trying to figure out what do they have access to help replace that lost income. And that's going to depend on, are they taking short amounts of time off? Because maybe paid time off, sick leave can

help replace that lost income. If they're taking extended periods of time off, then we would be looking to see what types of disability insurance benefits they may have access to.

Holly: You mentioned short time versus extended. Is there a time limit between short time and extended?

Monica: Well, it depends on what we're talking about. So, when we think about time off and wage replacement, there's sort of two columns to think about. The first is about what exists that's going to help people have job-protected leave? And I say it that way because a lot of times people don't realize that sick time or vacation time is not job protected. If you're in at-will state or you're an at-will employee, you can be let go for any reason at any time as long as it's not discriminatory. And so, we want to make sure that if someone is taking time off, they're taking as much job protected leave as possible. So that might be under the Family & Medical Leave Act, or the FMLA, or state and local leave laws that provide similar job protection. When we're talking about the FMLA, that is limited to 12 weeks in a 12-month period.

Elissa: So, you mentioned this very briefly, but I'd like to dig a little bit more into Social Security. And now there's disability income or SSDI and then supplemental income or SSI. What are each of those, and who is eligible for that?

Monica: Those are two programs run by the Social Security Administration, so they're federal programs, and they're both long-term disability insurance programs.

In order to have access to either one of these programs, someone has to show they cannot do their job, they cannot adjust to a new job, and they have a disability that has or is expected to last for a year or longer. So, when I say long term, I really mean these are long-term programs.

Now, the standard of disability is the same for both programs, but eligibility is different. So, supplemental security income or SSI is based on having a lower income



and a low asset level. So again, just like Medicaid, we're talking about things like retirement accounts, bank accounts, savings accounts. So, that's SSI, and the asset requirement is very low. It is \$2,000 for an individual.

Elissa: So, we're talking that's money in savings? Is it just liquid cash? Are we talking about like owning a home?

Monica: So, Yeah, there are things that are disregarded, so a single home, a single car, a burial plot worth a certain amount. But let's say someone has a life insurance policy that has a cash value of more than \$2,000. That's not typically thought of as liquid, but that would push someone out of eligibility.

Elissa: Wow.

Monica: So, we really are talking about a very low income and asset requirement for SSI. Typically, individuals who are eligible for SSI are also eligible for Medicaid as their health insurance option.

Now, the other program is Social Security Disability Insurance or SSDI. And this program is based on having worked and paid into the Social Security system in those working years. And so, this is not about having assets at all. It means you cannot work due to your disability.

Elissa: So somebody that was say a young adult who's maybe only been working for a year or two, is this something they might not qualify for, even if they have a disability that's going to last longer than a year?

Monica: It really does depend. So, basically, you have to have work a certain number of quarters in order to be vested and be eligible for the program. The number of quarters you need does depend on age. So, for someone over 31, you have to have 40 quarters. You can only earn 4 quarters a year, so generally it comes out to that you've worked, 5 of the last 10 years.

Elissa: Okay. Now, what about a diagnosis that's on the compassionate list?

Monica: Yeah, so this is a question we get a lot, and there's a huge amount of confusion around it. One of the challenges with SSDI and the Social Security Administration in general is it is not a speedy process. It can take 14 to 18 months for an application to be processed.

There are a couple of programs that speed up the application process. One of those programs is the Compassionate Allowances List, and this is a list of all sorts of diagnoses that the Social Security Administration has decided are going to be presumptively eligible. It is not a guarantee someone's going to get SSDI if they have a diagnosis on this list.

The way I think about it is there's this huge pile of applications the Social Security Administration has to go through. Having a diagnosis on the Compassionate Allowances List kind of gets your application put in a different pile that's a little shorter.

So, it just speeds up that application process. It does not guarantee that you're going to get benefits. It also doesn't eliminate the five-month waiting period. So, with SSDI, the Social Security Administration will pick a date that they have decided your disability began. And that's typically the day you stop working, so a lot of people think, well, I was diagnosed on this date. Shouldn't it go back to that, and that's not really what they're looking at. What they're looking at is when did your disability impact your ability to work?

And for a lot of people, that's not until maybe a few months in because it's not until they start getting the side effects of treatment that they figure out they can't work.

Elissa: Right.

Monica: So, the disability onset date is picked by the Social Security Administration, and then there is a five-month waiting period from that date before you can get access to benefits.

Elissa: Now, if you qualify though for SSI, does that waiting period go away?

Monica: So, that's a really interesting question. There are a couple of strategies to fill that five-month waiting period, and one of the strategies is to actually apply for both SSI and SSDI, if you're eligible. SSI, there is no waiting period, so benefits would start. Typically, what happens when someone qualifies for both is that their SSDI payments push them out of eligibility for SSI.

But the SSI does help fill that five-month gap. Other strategies to fill that five-month gap might be having a private disability insurance policy. So, I think one of the most common examples these days is Aflac® [Insurance]. Right, we've all seen the duck commercials. Those are examples of private disability insurance policies that typically have a much shorter waiting period and kick in faster so they can help people pay their bills. And I don't mean healthcare bills, I mean any bills – food, housing, utilities sooner than SSDI is going to kick in. There are also a handful of states that have state disability programs, but there's really just only a couple of those.

Elissa: Okay. So, I want patients and their caregivers listening to understand then that, it can be quite a long time because it's a five-month waiting period. I remember when, I was on it when I was doing AML, and that is on the Compassionate Diagnosis List; and it ended up being about seven months from the time of diagnosis until the time the first check was received. And that was something that I was not anticipating, and so just living off of savings for seven months.

Monica: And that is a pretty fast experience. We know people who are waiting for two or more years. Now, that could be, again, because of processing times; but it could also be that your application is denied the first time. About 60% of applications are denied on the first round. And so, if someone gets a denial, similar to health insurance, we don't want them to take no for an answer because there are actually five levels of appeal for disability insurance, for Social Security Disability Insurance. And as people go through the appeals process, the rate of approval does go up.

In those situations, someone could get retroactive payments from application date back to disability onset date, minus that five-month waiting period.

Now retro benefits are capped at 12 months. There's also payments called back payments, and this is about the fact that the Social Security Administration does take a really long time to process applications. And so, someone might have been eligible for payments during certain months, but they didn't actually get the check because the Social Security Administration takes so long.

So, back payments are from the date of approval back to the application date. So, there's two types of payments. So, someone might get a check in their first month of receiving benefits, and it could be pretty substantial because it includes retroactive payments and back payments. So, we do want people to also recognize like that's not the check you're going to get every month.

Elissa: Right.

Holly: Yeah.

Elissa: That's always good to know. Now what about once that patient starts working again? So, they start at a transition period to eventually move off of benefits. Could you tell us a little bit more about that?

Monica: The Social Security Administration has a number of programs to help people return to work, and collectively they're referred to as work incentives. Lots of different programs. I won't get into all the details, but for anyone who's listening, we have tons of resources on disability insurance to try to make this more bite size and digestible on *TriageCancer.org*.

One of the most valuable, in my opinion, programs is a trial return to work period. This is a period of time where someone can try to go back to work, and they can continue to receive their SSDI benefits while they are working for up to nine months. Now, those nine months don't have to be in a row. You actually have five years to try

to get to the nine months. So maybe you go back in January, and you earn over the amount, called the substantial gainful activity (SGA) amount. That's going to count as a month towards your trial work period. But then in February, you're drained. You can't work. You don't earn over the SGA. That won't count as a month. March, you don't make it. But then in April you start working again. You earn over, that's another month. And once you've worked nine months, your trial work period is over. Then you enter in another phase called an extended eligibility phase where any month where you earn more than SGA, you don't get your SSDI benefits. But if you earn less in that month, you do get your benefits.

Elissa: Okay.

Monica: So, the point here that I'm trying to make is it phases in the ability to try to go back to work because sometimes post-treatment you don't know always what it's going to be like, right? And so, it might take more time than you expect to get back to where you are fully able to work, earning hopefully what you were earning before the diagnosis. And I think what the real goal behind these programs is to give people the security to be able to try to go back without the fear of "it took me so long to get these benefits, what happens if I can't?"

Elissa: Right. We really don't know how it's going to be. I remember when I went back to work, I was just working four hours in a day. I think I worked 12 hours a week, and I was so exhausted I could barely drive home. And that was not something that I had anticipated, so I was very grateful for that transition period, so I could feel comfortable with working back slowly and ramping up to where I felt like I could do this.

Monica: Yeah, absolutely.

Holly: We've now gone over quite a bit of the financial impacts a patient or caregiver may face. So, let's discuss some solutions. During their treatment, what financial assistance may be available to the patient?

Monica: Well, from my perspective, I would not start with financial assistance. Really, I want someone to look really holistically at their financial big picture and thinking about what's available before they get to the financial assistance.

And here's why I say that. There is not enough financial assistance to go around.

Elissa: Right.

Monica: And I think LLS does an incredible job supporting your community. Financially, you have some incredible programming, but there might not be people who are eligible or even if you could give financial assistance to everybody who asks, that financial assistance typically isn't going to solve all the financial problems someone is experiencing. Or maybe it's going to solve it in the short term, but what about the long term?

And so, we want people to think about what's causing the financial hardship. Do you have huge out-of-pocket costs because your health insurance isn't adequate? Maybe you're trying to come up with money to pay a bill because insurance denied it. Well, then in that case, let's appeal that decision and see if insurance is going to cover it.

Is it because you have to stop working? Well, let's talk about reasonable accommodations and can you stay at work? Or maybe the FMLA or state leave laws to take time off so that you can take care of yourself and get back to work. If you do need to take time off, let's talk about do you have access to disability insurance in some way, shape, or form because that's going to help replace lost income.

So, we want people to think about all these other pieces before "let's ask for financial assistance". Not to minimize the need, because there was still going to be need for that financial assistance; but again, it's about being sort of more holistic and trying to treat the problem more systemically. Now, if someone does need financial assistance, there's lots of places you could go. I've mentioned LLS has some really wonderful programs, looking to community organizations that might provide financial assistance.

When we talk about financial assistance, we generally want to leave people with the message that you have to be creative. Sometimes people get tunnel vision, understandably so, of "I can't pay my mortgage. What do you have for mortgage assistance?" There might not be options for mortgage assistance. So, then we might say, "Well, hold on, are you eligible for utility assistance and food benefits? Can we get you gas cards so that the money you have set aside to buy food and gas can get shifted to help make your mortgage payment?"

And I think that sounds really obvious to people who maybe aren't in a crisis moment, but when you are in that crisis moment of what am I going to do, how am I going to pay those bills, what's going to happen to my house, can I feed my kids? – sometimes those more logical suggestions aren't the first things that come to mind.

Elissa: So, what about travel costs? Whether patients are local or maybe they live a few hours away from the hospital, what can they do?

Monica: So, travel is a huge problem, and it's one that I don't have a great answer for. I think people have to be really resourceful, so there are programs out there. For example, the American Cancer Society has a program called, "Road to Recovery." But that is very volunteer-based, and so if there aren't volunteers in somebody's area, that might not be an option. I know some hospitals and community organizations might provide gas cards, but I've got to tell you, the transportation one is, there's no great easy answer for that one.

Elissa: Yeah, that's tough. And we will have information about our travel assistance program in the show notes that can hopefully help, at least some people, with their travel. But yeah, that is a really tough one for a lot of patients.

Monica: Yeah.

Holly: I'd like to bring up the new Medicare change called smoothing that will be implemented next year. We discussed in our Medicare episode a few months ago,



which we'll link in the show notes, but could you share what smoothing is and how it will benefit patients?

Monica: Sure. So, this is a really exciting upcoming change to how prescription drugs are going to be covered under Medicare Part D. And prior to this year, there was no out-of-pocket maximum for Part D.

Holly: Wow.

Monica: So, yeah. So, even when someone reached what's called catastrophic coverage, they were still responsible for 5% of their medication costs. As you all know, cancer drugs are expensive; and so 5% of expensive is expensive. And there's no out-of-pocket maximum, so people were forced to figure out how to pay for this.

Elissa: And when you're on a fixed income, I mean what do you do?

Monica: That was legitimately going to be my next statement. When we stop and think about who is on Medicare, people over the age of 65 who often are on fixed incomes and individuals with disabilities so severe they cannot work. Now, also some of the other programs that exist, like from pharmaceutical companies that can help people with other types of insurance, are often not available to people on Medicare. So, it was a real practical problem, and it was pushing people into poverty, people were skipping doses or not adhering to treatment because they literally could not buy the medicine.

Thankfully, in the Inflation Reduction Act, we've had some changes to how Part D's going to be covered. I know you guys just had a show on this. So, for 2024, there is now an out-of-pocket maximum, so that's new for this year. The dollar amount does depend if someone is taking a generic or a brand name drug. So, if someone's taking a brand name drug, the dollar amount is about \$3,000. If someone's taking all generic drugs, it's going to be about \$8,000, which I'm not saying isn't a lot of money. Of



course it is. But when we compare it with last year where there was no out-of-pocket maximum, \$8,000 starts to feel a little bit more reasonable.

And then even better news, next year in 2025, that out-of-pocket maximum is going to be \$2,000 for everybody.

Elissa: Wow.

Monica: So, really significant changes that I just feel like aren't being talked about enough that are going to help the cancer community tremendously in this conversation around financial burden.

Now, you asked about smoothing, and that is a piece of this puzzle, starting next year, where if someone is taking an expensive drug, they could get to that \$2,000 figure in January. Many of these individuals don't have \$2,000 in their bank account to just write a check to buy their drug. And so what the smoothing concept is it allows someone to spread out the payments to get to their \$2,000 through the year.

I've been conceptualizing this as like a payment plan, almost. So, instead of having to come up with \$2,000, you get to spread out your costs throughout the year. We're still waiting on the details of how this is all going to work. So, for example, is someone automatically going to be enrolled in smoothing, and it just happens behind the scenes? Is it something that they have to proactively go and ask their pharmacist, "Enroll me in this program?" So, we're still waiting on the specific details of how this smoothing is going to work. But at its core, the point is to try to help individuals over 65 and people with disabilities afford their prescription drugs.

Elissa: Right. And for our listeners who are on Medicare, don't you worry. We will keep you updated as the changes get closer as we learn any information. So, be sure to stay tuned to the LLS website.



Now, let's talk about after treatment. So, certainly between medical bills, maybe loss of income, it might take a while to come back financially from this. What can a patient do to restore their financial health?

Monica: Again, this is one of those answers where it's going to depend on the person's situation, what they have access to. Certainly, stopping and reassessing where someone is currently is step one. And this can be really challenging, especially if someone, was plugging along in life and was doing all the things, saving for retirement, adding to the savings. All the things that we try to do as adults and then cancer diagnosis derails all of that.

It can be very hard to kind of reset and figure out now what, but that is actually what's required. So, taking stock of your current financial big picture, what assets do you have, what debt do you have, what are the sources of that debt, and can we deal with them in a certain way? Again, I sound like a broken record, but if they have huge medical bills because insurance was denying those claims, if those claims were recent enough, maybe appealing them. Certainly, if someone is in a situation where they do owe a large lump sum to a healthcare provider, for example, can you negotiate with that provider? Lower lump sums to erase the debt? Payment plans, for example.

And then also thinking about are you ready to go back to work? Sometimes people will say to us, "I would love to go back to work, but I'm still dealing with side effects." Or, "I still have medical appointments that have to happen during work hours, so how could I possibly go back to work?" And then we're going to talk to them about, well, there might actually be things that could help, like reasonable accommodations, so you could get time off to take those doctors' appointments or to deal with your side effects.

So again, knowledge is power here. And so, understanding what all of your options are, that is going to help someone figure out well how do you move forward from here?



For some people considering bankruptcy might be appropriate. I generally don't start with bankruptcy because it does have a very long-lasting impact on somebody's life. And it's not appropriate for everybody.

So, maybe sitting down with a financial planner might be a good solution to figure out if what they are doing is going to help rebuild that financial health. There are consumer credit counseling agencies in every state that can help people assess budgeting and, where they should be putting money and sometimes even, yes, if bankruptcy is appropriate.

Elissa: All right, that is some good advice. And I assume that you have some information on the Triage Cancer website that patients can look at?

Monica: We do. We have tons of information in a variety of formats. So, we have quick guides that are sort of snapshots of the topic, really easy to read. We have longer guides. We have really in-depth interactive website modules. We know not everyone wants to read about this. It's not the most, invigorating topics. So, we have short, animated videos and live and recorded webinars. We have an upcoming conference, so there's tons of ways to get this information.

I also will just say we have a program called our Legal and Financial Navigation Program. And this is where individuals who have been diagnosed or caregivers or advocates or healthcare professionals can fill out a form on our website and schedule a short call with us. We don't provide legal representation or financial assistance as an organization, but our goal on these calls is to explain to people what their options are, what programs they might have access to, next steps they could potentially take, questions to go back and ask. We're really trying to demystify these topics and help people navigate their situation because it isn't going to be a one-size-fits-all answer.

Elissa: Right, and that is so good to know.



Now, our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." So, when it comes to the financial impacts of cancer, what would you say to patients and their families to give them hope after a diagnosis of cancer?

Monica: I think what I would say is, as cliché as it sounds, you aren't alone. There are lots of organizations and healthcare providers out there who want to support you, including LLS and Triage Cancer. I'd also say there may be more options than you realize, and so making sure you understand all the options is key before making decisions on how you're going to move forward.

Elissa: That is good advice.

So, thank you so much, Monica, for joining us today. You've shared a ton about not only the financial impacts but solutions for them and what patients can do. And for our listeners, be sure to check out our show notes. We will have a ton of links in there, so that you can find information from Triage Cancer, from LLS to hopefully get you through the cancer experience a little bit easier. And so, thank you again, Monica. We really appreciate you.

Monica: Thank you so much for having me. I so appreciate the partnership we have.

Elissa: Thank you.

And thank you to everyone listening today. *The Bloodline with LLS* is one part of the mission of The Leukemia & Lymphoma Society to improve the quality of lives of patients and their families.

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In addition to the Lounge, we could use your feedback to help us continue to provide the engaging content for all people affected by cancer.

We would like to ask you to complete a brief survey that could be found in the show notes or at TheBloodline.org. This is your opportunity to provide feedback and suggested topics that will help so many people.

We would also like to know about you and how we can serve you better. The survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact LLS staff, please email TheBloodline@LLS.org.

We hope this podcast helped you today. Stay tuned for more information on the resources that LLS has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by a blood cancer? LLS has many resources available to you – financial support, peer-to-peer connection, nutritional support, and more. We encourage patients and caregivers to contact our Information Specialists at 1-800-955-4572 or go to LLS.org/PatientSupport. You can find more information on financial resources at LLS.org/Finances. All of these links will be found in the show notes or at TheBloodline.org.

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