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Blood Cancer United

The Bloodline with Blood Cancer United Podcast

A podcast for patients and caregivers

Episode: 'Advocating for Yourself: Insurance, Finances, and Your Rights'

Description:

Cancer affects more than your health. It can impact your finances, insurance coverage, employment, and daily life. In this episode, Monica Fawzy Bryant, Esq. of Triage Cancer joins us to discuss common financial and insurance challenges patients and caregivers may face after a cancer diagnosis, including understanding health insurance, managing medical debt, appealing insurance denials, finding financial assistance, and avoiding gaps in coverage. Monica also shares practical resources and strategies to help individuals make informed decisions and reduce the financial stress that can come with cancer.

Transcript:

Elissa: Welcome to *The Bloodline* with Blood Cancer United. I'm Elissa. Thank you so much for joining us on this episode.

Today, we are speaking to Monica Bryant, a cancer rights attorney and Chief Mission Officer of Triage Cancer, a national nonprofit that provides education on the practical and legal challenges faced by people diagnosed with cancer and their caregivers. A nationally recognized speaker and author, Monica specializes in cancer-related issues,

including health insurance, finances, employment rights, disability benefits, and access to care. Welcome, Monica.

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

Elissa: Well, thank you for being here with us today.

So, our episode is on navigating financial and insurance issues after a cancer diagnosis. This is certainly a topic that tends to be top of mind from diagnosis through survivorship, but let's start at the beginning. When someone is first diagnosed with cancer, what financial and insurance issues should they think about right away?

Monica: I always think it's helpful to take a beat and do an assessment of what coverage somebody currently has. What we generally find is that people don't really understand how health insurance works. It's incredibly confusing in this country.

Elissa: Yeah.

Monica: It's almost like having to learn a whole new language that very few of us are ever taught before we need it. And so, usually, we find that people don't really understand their policies, they don't understand the amount of coverage they have, they don't understand what they're going to be expected to pay out of pocket. So, I

think early on, it's really helpful to, again, take that beat, dig in a little bit to the existing policy, and understand what coverage somebody has.

Elissa: Now, could there be any surprises that may happen once somebody is already into treatment that patients may need to be aware of?

Monica: Possibly. We definitely see situations where someone may have been down a path towards their diagnosis and maybe they sought out specialists; and they may not have realized that somewhere along the way that specialist or a hospital or other type of provider isn't in network. And not only does that mean that they could be paying more for that care, it often also means that whatever they do pay out of pocket doesn't end up getting applied to their out-of-pocket maximum. So, it can mean that, overall, they're going to be spending more money out of pocket.

So, I always suggest that people ask those questions up front when they're making appointments to double-check that the providers are in network. I think the other thing that people don't always realize is they might say, you know, "I have X health insurance," and they'll use a name of a company. But they don't always realize that that company might have hundreds of different health insurance policies.

Elissa: Ah, uh huh.

Monica: So, when they're asking, when they're making that appointment, I suggest use the full name of the plan. "I have Gold Leaf Plan 100. Do you accept that?" So, that

they can be really sure that the providers are in network and, hopefully, keep some of those out-of-pocket costs down.

Elissa: And speaking of surprises, we've heard a lot about the surprise bills, right, and how those are not allowed anymore. Could you get a little bit more into that and explain how that works and what is or isn't allowed?

Monica: Sure. So, surprise bills are really where someone's done their due diligence to make sure that the providers they're seeing are in network. But again, somewhere along the line, they might find that one of those providers was out of network. And this is super common in the context of surgery, for example, where the hospital's in network, the surgeon's in network, but then after surgery, someone finds out, "Oh, the anesthesiologist was out of network."

Elissa: Oh!

Monica: And now they're faced with a huge bill. Some states over the years have passed state laws to try to address this issue. But we now have a federal law called, "The No Surprises Act," and it went into effect January 1st of 2022. And what that law says is in those cases where people really did the best they could to make sure that they were going to in-network providers; but, it turns out, an example like that happens, that now individuals can actually submit those bills to the No Surprises Help Desk. That help desk with then make the provider and the health insurance company

negotiate because what's supposed to happen is that that provider is supposed to be treated as an in-network provider. So, ultimately, what that means, it takes the responsibility off of the patient. It doesn't mean the patient pays nothing. It means that they have to pay whatever they would have had to pay towards an in-network provider.

Elissa: Okay. Is there a website that they can go to that we can put into the show notes so they can look up more information if they do feel like they have a surprise bill?

Monica: Yep, there's both a website and a phone number they can call.

Elissa: Perfect. We will have that in the show notes for the listeners who would like to look more into that.

So, we also hear the term "financial toxicity." What does that mean, and why is it important to address early?

Monica: Financial toxicity was a term coined in 2013 by researchers out of Duke University. And what they looked at was how the financial impact of a cancer diagnosis and subsequent treatment can be as significant, if not sometimes more significant, than the physical toxicity that many cancer treatments can cause.

And what was really interesting about this particular research is they didn't look at just how that financial burden happened in an acute way during active treatment, but how

there's often a long-term impact. And when we talk about financial toxicity, we're not really talking about the cost of care because even if care is very, very expensive, if someone has adequate health insurance coverage, they can keep that financial toxicity to a minimum.

But health insurance status is just one of the contributing factors to financial toxicity. We also know the employment changes that can occur after a diagnosis can impact finances, and that's both for the person who's diagnosed that might experience employment changes, but also potentially for any caregivers that might have employment changes. And it might impact the overall, familial unit's financial health. And then, as you know, all the things that happen in life that might impact our finances, like moving or relationship changes. Those things keep happening, even after a diagnosis.

Elissa: Yeah.

Monica: And they can just continue to compound the financial challenges that people experience. And so, that's really what we are about at Triage Cancer is to give people the information and the tools that they need so that they can make informed decisions around things like health insurance and employment so that, hopefully, they can minimize that financial toxicity.

Elissa: Right.

And then a lot of people then can also have, the bills compounding as well, right, and leading to medical debt?

Monica: Medical debt's a huge problem because, again, if someone doesn't have adequate health insurance and they have huge out-of-pocket expenses, they may not be able to pay those expenses at the time. And so, there are certainly some strategies that people can utilize. We always recommend having conversations with providers. So, let them know that you are experiencing financial challenges. Negotiate. So, can you have more time to pay the bill? Can you get a payment plan? Maybe they're willing to accept a lower lump sum instead of having to pay the entire amount.

So, it's hard because I think a lot of people don't want to talk about finances generally; and they certainly don't want to talk about finances when it comes to their healthcare providers because that's not really what healthcare providers are there for. And so, it certainly is a challenge. Also, of course, there are organizations out there, like Blood Cancer United, that provide financial assistance to help people with medical bills as well.

Elissa: Yeah, and also that patients can sometimes apply for charity care at the hospital, right?

Monica: Absolutely. So, if the bills are related to a hospital stay or care received at a hospital, many hospitals are actually required to provide individuals with charity care.

That looks a little different in every place, but it's definitely something that people should be asking about at their facilities.

Elissa: Okay, that is good to know. So, then what about patients who just cannot afford their treatment? So, they've talked to the hospital. They've talked to the doctor, and they're saying to themselves, "I don't know how I'm going to pay this. I don't know how I'm going to pay my deductible or my maximum out-of-pocket." What should they do first?

Monica: Honestly, it's a real problem; and there isn't a magic solution to any of this. It is why we try to educate people upfront about making health insurance choices. Unfortunately, many Americans will simply pick the health insurance policy with the cheapest monthly premium. It goes back to that understanding that language because if people don't understand what a deductible is or what an out-of-pocket maximum is, they may not know how to make those choices. Again, outside of financial assistance and negotiating, there are limited options in this country.

Elissa: Yeah, and we'll have in the show notes, you did a video series with us for our "How Do I" series to talk all about insurance. So, if you are listening and you're just not sure how to choose a plan, what to look for, the deductibles that we're talking about, you can learn more in the videos that we'll have linked there with Monica telling us all about it.

So, then beyond treatment itself, what other cancer-related expenses do patients often overlook?

Monica: A lot of people don't think about expenses like transportation. So, in a lot of cities in this country, even just parking at hospital facilities can add up very quickly.

I think the other expenses are around the work piece. So, if someone, for example, works at a job where they're paid by the hour and they're now spending half their day in an infusion suite, that is an expense. That is money that is not coming in anymore.

So, then it's talking about, well, are there ways that someone can continue to work while they're in treatment? There are laws that exist that can provide tools to help people work through treatment. But if someone really does need to take time off, then it's about looking at what are the income replacement options; and typically, that's going to be disability insurance.

Elissa: And then are there other resources besides the disability insurance available? So, if they need some help with transportation, lodging, say if they need to go to a larger center that they don't live by, utilities or other daily living expenses?

Monica: Yeah, so there's lots of different financial assistance options out there. But a real challenge is that every single program has different eligibility requirements and applications. So, I've actually been told in the past that it's almost like another full-time job just to try to find the financial assistance options and do the applications.

And so, I have to acknowledge that it's not an easy thing to do. But one thing we do suggest for folks is that they think really creatively about the financial assistance.

So, you mentioned a couple places, like transportation or lodging or utilities. And if someone's in a situation where maybe they do need help with transportation costs, but they can't find financial assistance for it, then we would say to someone, "Well, do you have money set aside to pay for your gas bill?" If they do, is it possible for them to get utility assistance so then they can shift the money that they were going to pay for their gas bill over to parking costs, for example.

And it sounds a little bit simplistic to think about, but oftentimes when people are in that crisis moment, they're scared, they're worried about their health. Sometimes, those sort of logical things can be missed.

Elissa: Yeah. Now, I do want to ask a question for the caregivers listening today. What advice do you have for caregivers who are juggling employment and caregiving responsibilities? It's just so much to take on, especially if you might be losing one of your incomes while your partner or family member is going through treatment.

Monica: It's so true. It is absolutely a huge amount to take on. There are resources to support caregivers in a variety of ways. So, there's organizations that provide psychosocial support for caregivers. If someone is needing to take time off to serve as a caregiver, there are job-protected laws that might apply to their situation. So, one

of the most well-known is the federal Family & Medical Leave Act or the FMLA. Not everyone qualifies, unfortunately, for the FMLA. And it's unpaid. So, you might be able to take that time off and protect your job, but, to your point, if that's the only income coming in, that could be a real challenge.

There are limited income replacement options for caregivers in this country, unfortunately. And it's quite the patchwork. So, there is no federal paid family leave. Some states do have paid family leave to help support caregivers who need to take time off from work. And at TriageCancer.org, we actually have a chart of state laws that outlines the different states' leave laws, so that would be a resource if you're trying to understand what exists in your state. But like many of the things I talk about, I have to acknowledge that there aren't as many great support options for caregivers as I think there should be.

Elissa: Yeah, it's tough; and caregivers, we want you to know that we have a lot of resources available just for you and you can find a link in the show notes. So, now let's get into the insurance aspect of treatment. What can patients do if an insurance company delays or denies approvals for a recommended treatment?

Monica: Not take no for an answer.

Elissa: Yes, I like it.

Monica: And it is absolutely important for people to realize that through the course of being diagnosed and treatment, it is highly likely that they are going to experience a denial from a health insurance company. Unfortunately, as common as it is, many people don't realize that they have the right to appeal those denials. The details are definitely going to vary, depending on the type of insurance that somebody has. But at a minimum, they're going to have at least two opportunities to appeal that denial.

So, if we're talking about, perhaps, a policy that someone went out and purchased in the marketplace, there's an internal appeal, where you're going back to the insurance company and asking them to reconsider. But then there's also an external appeal, where you're going to an independent entity, and they are looking at the policy and the medical condition, and they are making a determination as to whether or not the insurance company should cover that service.

Elissa: Okay, and they would have to abide by that if the independent entity says they need to cover it?

Monica: Exactly. It's binding on the insurance company. And there's two times one might get a denial. They might get it before they receive the service. So, if a prior authorization has been denied and then they could also get the service and then it's denied after the fact.

If we're talking about a prior authorization denial, and the need for care is urgent, which in the context of cancer, it is often the case that it is urgent, someone can actually file the internal appeal at the same time as the external appeal; and they get an answer back within 72 hours.

Elissa: Yeah, I think those denials can be so frustrating for cancer patients. We're already going through so much; and I remember getting a denial when I was going through treatment for acute myeloid leukemia. And it was something that was part of the standard of care. It was just an injection that I got at the end of each chemo; and they denied the very last one after they'd approved every other single one. And it was so frustrating to go through it and, you know, finally got it taken care of. But, it's just so hard. It's an extra thing that's added onto the patients that we just really don't need.

Monica: A hundred percent, and it's not only a burden for the patients, it's a burden for the healthcare professionals.

Elissa: Oh, yeah.

Monica: When all they should be doing is providing healthcare, not handling paperwork with insurance companies. But it is, unfortunately, part of our system, which is why we spend so much time at Triage Cancer talking about it; and we have lots of different tools to help people navigate the appeals process. We have a state-

specific appeals toolkit that's coming out very soon. And then we also have an AI tool that will help an individual write the initial appeals letter.

Elissa: Oh, great.

Monica: So, it can be used by the patients or caregivers themselves to submit the appeal. Certainly, healthcare professionals can use it as well if they're trying to write one on behalf of their patients.

And so, it is important that people do the appeal, even though it is, to your point, so frustrating and one more thing that nobody wants to be doing. But it's important because (a) it'll hopefully help you get the care that you need. But (b), it also then signals to the state insurance commissioners that there might be an issue. Because if insurance commissioners start to see lots of appeals around a particular treatment or a company or around a specific condition, they can start to look at that as a pattern in practice and make some decisions based on that. But if they don't ever see the appeals coming through, from their perspective, there must not be a problem.

Elissa: Oh, that's good. So, then patients are not only helping themselves but potentially other patients and patients coming in the future for that particular diagnosis or treatment.

Monica: Exactly.

Elissa: Oh, that's great. Now, are there situations where patients should request help from a financial navigator or social worker or patient advocate?

Monica: I think there's lots of different situations where that might be helpful. But I also have to acknowledge that those types of support professionals may not be available in every cancer center where people are getting treatment. If someone like that is available, I always think it's great to just reach out, ask them questions about how they can be supportive. Are there things that maybe I'm not thinking about? It's going to be very different in every location, but I always think that it can't hurt to ask for help. And if the individual in your treatment center can't provide that help, maybe they can be a connection to other resources outside of where you're receiving cancer treatment.

Elissa: Okay, so if the patient was looking for that, so they should ask their oncologist or nurse manager and say, "Hey, I would like some help to deal with this issue or look into finances" or something like that?

Monica: Yeah, I think that's a great start. And so, "Is there a social worker that I might be able to speak to?" "Is there a financial counselor that might be able to sit down and explain my insurance coverage to me and what the most is that I'm going to pay out of pocket?" And then I think that if someone can't connect one on one with them, then it is about reaching out to Blood Cancer United or Triage Cancer to ask what support we can provide.

Elissa: Yeah, just like those videos that we just talked about earlier where we talked about all the different options of insurance and particularly if you're coming up to Open Enrollment, that may be a good time to talk to somebody that, "Hey, am I even on the right insurance plan? Could I be on a better one?" And then there's other questions, maybe copay assistance cards? Could you share about that?

Monica: Absolutely. So, it's a form of financial assistance that is designed to help people pay for those out-of-pocket expenses because it's important to remember that insurance is often only going to cover a part of all of your treatment costs. You're still going to be responsible for some money out of pocket, at least until you hit your out-of-pocket maximum. And to your point earlier, some people struggle with paying those extra expenses out of pocket. And so, copay assistance cards help pay for those out-of-pocket costs.

But same condition that we were talking about with respect to the other types of financial assistance, every program has different eligibility, different uses for it. So, it does take a little legwork to be able to work through what you might have access to.

Elissa: Now, are there insurances that patients may want to avoid? I know that not everything is on the Healthcare Marketplace.

Monica: I'm hesitating slightly because we are about to face some really big changes to our healthcare system in 2027, including major changes to how the ACA marketplaces operate.

Elissa: Yeah.

Monica: So, we don't a hundred percent know what it's going to look like next year; but what we do know is that because the additional financial assistance that we got during COVID expired at the end of 2025, people saw huge increases in their monthly premiums; and it really made health insurance unaffordable for them. And the reports are coming out that things are going to increase even more next year. And so, people are looking for alternatives.

So, what are those alternatives? They might be short-term plans, so plans that last less than a calendar year. The challenge with that is that they don't have to comply with a lot of the consumer protections that we got in the ACA. They also can end midyear, and they don't trigger an opportunity to get a new plan. So, someone could be left uninsured midyear.

Other options might be association plans or what are referred to as health share plans or healthcare sharing ministries. And these actually aren't health insurance, but rather it's a group of people who have come together and agreed to essentially put all of their

money into a pot and pay for each other's medical care, which sounds quite lovely, to be honest, of communities working together-

Elissa: Yeah, and that sounds like an insurance pool, by itself.

Monica: Right, right.

Elissa: Yeah.

Monica: The challenge though is that with these, it's not insurance. And so, there's no requirement that the group pays for your medical care. So, if someone has a very expensive medical condition that will drain the pot of money, they might be left in a situation where they've paid into this pool, and now it's not going to cover their expenses. And there's very little recourse if that were to happen.

So, I say all of this because prior to this year, we would have really steered people away from these short-term plans and away from healthcare sharing ministries because there were more comprehensive, affordable options for people to pick from. But that may be changing.

Elissa: Yeah. So, really, just want to make sure you're looking for something that is covering what you need or hope to get covered what you need?

Monica: That would be the ideal situation. But again, we don't have a crystal ball, so we just have what we are anticipating is going to happen. And it is absolutely possible

that Congress might act between now and next Open Enrollment and reinstate that additional financial assistance. And so, for any listeners that feel passionate about this topic, I would strongly suggest that they reach out to their elected officials and share their stories about why this is so important to Americans dealing with cancer.

Elissa: And those are the Enhanced Premium Tax Credits, correct?

Monica: Exactly.

Elissa: Okay. And then the protections that you were talking about, so those are more, you know, making sure that they are required to cover things and that they don't look at preexisting conditions to give you that coverage, those kinds of things?

Monica: Yeah, that's exactly right. So, short-term plans, for example, can charge someone more if they have a preexisting condition. They can deny covering things related to their preexisting condition. They can exclude whole categories of care like prescription drugs or chemotherapy. And so those are the types of things that the ACA really stepped in to try to make sure that comprehensive coverage included all of those things. That's what most of us think our insurance should cover.

Elissa: Yes.

Monica: But these short-term plans were carved out of the ACA protections.

Elissa: Unfortunately, it has seemed like that you don't know that it's not covered until you end up needing it; and then you find out that all of a sudden, got a very big bill.

Monica: That is exactly what happens. People will call us and say, "My insurance isn't covering my chemotherapy," and we think how is that possible? They have to cover chemotherapy. And then we dig into their story a little bit more, and we find out that what they have is one of these short-term non-ACA-compliant plans; and they are allowed to exclude chemotherapy.

Elissa: Wow.

Monica: And the problem with these plans is that it's not always obvious on the frontend that what you are signing up for is a short-term plan.

Elissa: Yeah. And especially for somebody that, you know, seemingly on the surface, very healthy. So, you know, "I'm very healthy, haven't had any problems." That is not always the case, and so, that insurance needs to be there if something does happen and to make sure that it does get covered.

Monica: You took the words out of my mouth. I always find it so interesting how people look at health insurance so differently than they look at other types of insurance. Like car insurance, for example. No one buys car insurance because they're hoping to get into an accident and needing to file a claim, right?

It's the same thing with health insurance. It's the idea that you have the insurance coverage to protect you in a worst-case scenario. But most of us don't think of that prior to a serious medical diagnosis.

Elissa: Yeah. I'm sure that people listening right now are thinking, 'Well, can't I just get a catastrophic plan?" How does that work?

Monica: Catastrophic plans are a very specific type of insurance that used to be limited to a very specific group of people. So that was going to be people under the age of 30 or who didn't qualify for financial assistance.

And so, what these plans are is they're very limited in scope before you hit your deductible. So, like you get one doctor's visit. If you need additional care, you first have to hit your deductible, which can be upwards of $15,000. And then the plan will start providing coverage. Most people, myself included, would have a very hard time coming up with $15,000 to access healthcare.

Elissa: Yeah, yeah. That's a lot of money right out of the gate. Especially if you do get cancer, and you can't work or if your spouse can't work. I mean, then what do you do? And then that leads to more medical debt.

Monica: Exactly. It's a very vicious cycle, which is why I started with the most important thing that someone can do is understand their health insurance; and to the extent possible, make sure that it's adequate coverage. It's also why the issue around

the enhanced tax credits and the additional financial assistance was so important for our community because we saw millions of people were able to access health insurance because of it who have now had to drop that coverage because they simply cannot afford it.

Elissa: And then for those who still have health insurance, it's not a good thing when a lot of healthy people drop off the insurance roles, correct?

Monica: Yeah. That's such a good point that I think a lot of people don't take into consideration, especially when talking about these policy issues is that in order for our system to work, everybody has to buy in to the system to basically balance the risk. So, the super healthy people who are paying in help cover the cost of people who do get a serious medical diagnosis. And over time, and as the pool is expanded, that risk evens out. To your point, if the healthy people stop buying in, and the only people that buy in are ones with very expensive medical conditions, our system is going to fail.

Elissa: Yeah. I mean if you look at it just by the number, so say ten people are in a plan and two people are sick, have cancer or some other serious illness, and those six or seven people drop off of that plan, now it's a plan of only two or three people putting in money to try to pay for basically everybody. And that's just impossible to do. So, that will potentially raise costs across the board for everybody, I would assume including the amount that the hospitals have to charge as well.

Monica: Absolutely. And this also comes up when we have conversations around Medicaid work requirements. So, lots of times people will say, well Medicaid work requirements are a great thing. People who can work should work. It is a reasonable argument.

The challenge is that, especially people in our community, may not be able to do the paperwork associated with work requirements. And so, they may end up losing access to Medicaid, not because they're not eligible, but rather because of administrative reasons. So, we're going to see people lose access to coverage because of the Medicaid work requirements. We're going to see people lose access to coverage because of these increased marketplace costs.

There's some immigration rules that are going to impact access to Medicare, and all of this together means we're going to have more people in the country uninsured. Well, where does someone who's uninsured go if they need medical care?

Elissa: Yeah, they go to the Emergency Room; and that's the only place they can go because they have to be accepted until they get stable, I believe.

Monica: Correct, so there's a federal law that says in emergency situations, providers have to provide the care, regardless of insurance status. But when people go in without insurance and they get care, that's what hospitals call, "uncompensated care." And then when uncompensated care rates get so high, hospitals have to make

decisions to stay financially afloat. And that usually means closing the most expensive departments to run. What's the most expensive department to run in a hospital? It's actually the Emergency Room.

Elissa: Oh, the Emergency Room, okay. So, they'd be closing Emergency Rooms at the hospital.

Monica: Correct.

Elissa: Wow.

Monica: So, even if you have the best health insurance through an employer and you get into an accident and you need to go to an Emergency Room, if the closest Emergency Room to you has closed, you are now impacted. And so, oftentimes people talk about these policy issues in a vacuum, as if it is just one thing. But the reality is in our system, everything is interconnected.

And we know that also, with Medicaid expansion in the states that expanded their Medicaid programs, health insurance premiums for everybody went down. So, there's, to your point, a financial impact that everybody is impacted, not just the one who has marketplace insurance or who has Medicaid but all of us. And it's just a reality that I think we're going to see play out over the next year.

Elissa: Now, we'll get a little bit more into Medicaid in just a bit; but I would like to point out, since we've talked about medical debt and those increasing bills, that Blood Cancer United has a Medical Debt Case Management Program available to patients and caregivers at no cost where specialists can help you find the right insurance for you, help with insurance appeals, and also applying to charity care, like we talked about earlier.

We're going to take a quick moment to hear a little bit more about this program.

So, now, let's dig a little bit more into Medicaid. With the Big Beautiful Bill in 2025, some changes were made; and we talked a little bit about eligibility. Could you share what those changes are, when they are being implemented, if they've already been implemented, and then if there are any eligibility issues that patients and their families should know about.

Monica: So, I'll take a quick step back. Medicaid is the federal program for individuals with low incomes and typically low assets, so that's things like a bank account or a second car; and they're able to walk through a door. In the cancer community, it was often the door called the Aged, Blind, Disabled Program.

In 2014, the Affordable Care Act expanded access to Medicaid and created a new door, and the new door was just based on income. So, they didn't look at assets, they didn't look at if you had a disability. It was just based on having a low income. And

this was a really big change that was supposed to happen across the country. The Supreme Court got their hands on the ACA and essentially made this expansion of Medicaid voluntary.

We have 40 states and Washington, DC, that have expanded Medicaid. We have 10 states that have not expanded. The reason I wanted to talk about that is because the changes in that bill that you just mentioned are mostly applying to that expansion door. So, for people who are not on SSI (Supplemental Security Income) but have lower incomes and are accessing Medicaid that way, there is going to be a new requirement that each month they participate in 80 hours of "work." And I put work in quotes if you could see me because it's not just a job. But it could be volunteering, community service, being in school. All of those types of activities count towards this work requirement.

Now, there are exceptions to the work requirements, including one for people who are considered medically frail. And that's the phase that was used in the law. And when the law was passed, we then had to wait several months to get regulations to explain what they meant by medically frail. What does that actually mean?

In June, we got those regulations; and what we learned was that their definition of medically frail was severe, for lack of a better word. So, it essentially made it that someone is only going to be considered medically frail if their health condition keeps them from working.

Elissa: Okay.

Monica: So, that's a very high standard. In fact, it's very similar to the Social Security Administration standard of disability.

So, for someone who has a cancer diagnosis and may be able to work, you know, a few hours a week, they might not actually qualify under this more significant definition of medically frail. So, several states have filed suit in courts to basically say like this isn't an appropriate definition of medically frail. It's too stringent, so we're waiting on the outcome of those court cases.

But to be perfectly honest, even for someone who meets that stringent definition, our concern, as I alluded to earlier, is that what are they going to have to do to show that they meet that definition to be exempted from the requirement?

We noted in the first year, people will be able to self-attest, so maybe that's a form where they just check a box; and they say, "Yes, I meet this definition." But moving forward, we don't know yet. Are they going to need the doctor's note, test results? If they need a doctor's note, how frequently do they need that doctor's note? Does it have to be every single month, and so there's lots of these details that we don't have yet because states get to make their own decisions. But they have to do it quickly because these requirements are supposed to go into effect no later than January 1st of 2027.

Elissa: Oh, okay. So then probably towards the end of this year we should have a pretty good idea in your own state of what the requirement's going to be for being eligible for Medicaid?

Monica: That is certainly the hope that we'll have that information from states. I will share that Triage Cancer is doing a webinar series in the fall around what we do know, so what states have already put out so far. So, we can certainly share the link for that. It's a free webinar that'll be available because we want to make sure that for people who still qualify for Medicaid and meet the exceptions, that they understand how they go about asking for it. What paperwork do they need to turn in? How frequently? How do you, turn it in online or do you have to mail it in? All of these little very practical details we want to be able to share with people as we get that information so that we can hopefully help people avoid losing access to their health insurance.

Elissa: Yeah, and you'd also talked about people losing Medicaid for administration reasons. So, there's also even as simple as not keeping your address updated, right, where you could just get kicked off the rolls?

Monica: Absolutely. I mean, that's exactly the kind of information that we want people to make sure your address is up to date, make sure you're checking your mail. Though if you get something in the mail, you see it right away and you know what you're supposed to do. Have a conversation with your healthcare team. Remind them that you get health insurance through Medicaid, and you might need a letter or

something to be able to stay on Medicaid. These are all sort of the places where we see people sometimes fall through the cracks, again, not because they're not eligible for the program but it's those administrative things.

Elissa: Yeah, and then I do want to bring up something that, as these conversations go on around, in social media and everything about, healthy people dropping off the rolls, insurance is so expensive, and then a lot of people are under the understanding that, if they get cancer, if they get another serious illness and they can't work, then they can just get onto Medicaid if they didn't have insurance. Is that the case?

Monica: Well, it depends on what state somebody lives in; and it's going to depend on their financial situation. Because if they live in one of those ten states that didn't expand Medicaid, then they are going to have to pay down everything that they have saved towards any sort of savings or retirement. They're going to have to have that dwindle down to $2,000 or less before they have access to Medicaid.

And we see that sometimes where people are chugging along in life, and they're doing all the things they're supposed to be doing – saving for retirement, putting money away in savings – and then they get a catastrophic diagnosis; and they basically lose everything because that's the way that access to Medicaid in those ten states works.

If someone's outside of those ten states and is in the Medicaid expansion, then they might have access to it if their income is below 138% of the federal poverty level. But

again, then they're going to have to meet the income requirements, as well as the work requirements or be able to show the exception.

My point being I don't think it's quite as easy as people think it can be.

Elissa: Yeah, yeah. And having had to be on Medicaid myself while I was in treatment because my diagnosis was on the compassionate list for Social Security Disability, so that was kind of an automatic Medicaid eligibility, but it's tough. And there's a lot of applications; there's a lot of things to go through. And then adding on these work requirements, I mean I know that a lot of patients will resonate with this, that I was so fatigued all the time in addition to going to the doctor's office several times a week, I could barely concentrate at the computer for an hour. Even once I started going back to work, working for four hours, I was practically falling asleep on the way home because it was so hard. And so, I can't imagine having to then think about working. Sixteen hours a week was so hard for me to do when I started kind of ramping back up. And that would be even worse, trying to do that while you're in treatment.

Monica: Absolutely. And even if you're not working, it's keeping track of the paperwork. And there's already so much paperwork. And, the other piece, I think, that sometimes people forget about in your example of, "Well, I'm just not going to have insurance. And if something happens to me, I can get on Medicaid." But if you don't have insurance, even getting to the diagnosis can be a challenge because many

providers won't even schedule an appointment with you if you don't have insurance coverage.

Elissa: Right. And that's something to think about as well that they might say, "Hey, we can't give you that super expensive treatment knowing that you don't have coverage and you're paying out of pocket." And while you can pay out of pocket and get a discount for a lot of things, I would think that cancer treatment would be a little more difficult to do that; and they might not be willing to just take that risk that you just won't pay for it.

Monica: Absolutely. And that's, if you're lucky enough to even get to the diagnosis uninsured.

Elissa: Yes, yes, because that's expensive in itself, getting scans, getting bone marrow biopsies, getting multiple tests done just to even find out the diagnosis. It's not a cheap thing. You can almost get to your out-of-pocket maximum by the time you're even diagnosed.

Monica: Unfortunately.

Elissa: So, how can patients avoid gaps in insurance coverage during treatment?

Monica: By thinking ahead. So, for example, if someone's in a situation where they had employer-sponsored insurance and they're thinking that they might need to take

a break from work, and that's going to impact their access to insurance, losing employer-sponsored coverage triggers a special enrollment period. And so, that's a period of time outside of that fall open enrollment period. So, it can be mid-year where you can purchase other insurance in the marketplace.

But if someone waits until they lose that employer-sponsored coverage to try to buy a new plan, they might end up with a month of, a gap where they don't have their employer-sponsored coverage and their marketplace hasn't started yet. But if they pick a marketplace plan before they lose the employer-sponsored coverage, then the marketplace coverage starts a month later, and I know that that's very convoluted, but the message really is don't wait until you've already lost coverage to figure out what your next step is because that's how you end up with gaps.

If someone is eligible for COBRA (Consolidated Omnibus Budget Reconciliation Act), which is the federal law that allows someone to continue their employer-sponsored coverage, sometimes that can also be used to bridge that gap. So, maybe you want the marketplace plan, but based on when you applied, there is going to be a gap, you can actually go back to the COBRA administrator and say, "I want to elect COBRA to continue my coverage, just until that marketplace plan starts."

And I will tell you this conversation around health insurance transitions and avoiding gaps is one of the most common things that we talk to people about at Triage Cancer. So, we have a number of resources to help people figure out what their options are.

And then how do you make choices if you do have multiple options? So, how do you make a choice as to what's better for you? Is it COBRA or is it marketplace plan? So, we have lots and lots of resources to help people do that.

Elissa: That's great. And you also spoke about that in one of the videos as well to talk about what to do if you lose insurance. So, you discussed COBRA. You discussed the special enrollment period, that 60 days before and after. And so very important information for patients to look at so they don't end up with a gap in coverage because that could delay treatment, that could cause a whole host of issues. So, we'd always recommend that patients, if you know that you're losing coverage, whether it is losing your Medicaid coverage, losing your employer-based coverage, that you look for the information right away and make sure that you continue coverage elsewhere.

Monica: I would also just add if you're moving and it's going to impact access to your coverage, that's another time. And it is funny because this moving piece, people aren't usually thinking about, like, great, I'll order boxes and bubble wrap. Oh, yeah, and I'll also check on my health insurance. And it's usually not until they've already moved and realized, "Oh, I can't see any providers in this new state that I'm living in because my old insurance doesn't cover me anymore."

Elissa: Oh, my goodness. I didn't even think about that. Yeah, because a lot of the insurances are state-based; and they have been for quite a long time. And so, yeah, I

didn't think about moving states and then not being able to have that same coverage anymore.

Okay, so our final question today. On our patient podcast home page, we have a quote that says, "After diagnosis comes hope." What would you say to patients and caregivers to give them hope after a diagnosis of cancer?

Monica: I would tell them that there are lots of places to seek out support in lots of different ways. Certainly, there's the support that friends and family can provide, the emotional support. There are some incredible healthcare teams and scientists out there. And then there are organizations like Blood Cancer United and Triage Cancer that exist to provide support so that, hopefully, people can survive the diagnosis with their homes intact, their jobs intact, their families intact, and with financial stability.

Elissa: That was very good advice. Well, thank you so much, Monica, for joining us today once again and sharing all about these really important issues that patients need to know, no matter where they are in their cancer treatment, if they're into survivorship. This is all very important information, and I know we've covered so much today.

To our listeners, we'll have many resources for you in the show notes of this episode, including more information on our Medical Debt Case Management Program, that video series we talked about to guide you through insurance or medical debt, as well as

important resources and worksheets from Triage Cancer. And then the other thing you had mentioned you know, talking to your legislators about the enhanced premium tax credits and how important they are and sharing your story. And we will also have information about our public policy and advocacy program so you can get involved. They make letter writing very easy to contact your state and federal legislators. And so, we'll have that information also.

But, again, thank you so much, Monica, for joining us today and sharing all your expertise. We really appreciate it.

Monica: Well, thank you for the invitation. We cherish our partnership with Blood Cancer United, and it's always a pleasure to chat with you.

Elissa: And thank you to everyone listening today. *The Bloodline with Blood Cancer United* is one part of our mission to improve the quality of lives of patients and their families.

Did you know that you can get more involved with *The Bloodline* podcast? Be sure to check out Subscriber Lounge where you can gain access to exclusive content, discuss episodes with other listeners, make suggestions for future topics, or share your story to potentially be featured as a future guest. You will also receive an email notification for each new episode. Join for free today at TheBloodline.org/SubscriberLounge.

In addition to the Lounge, we could use your feedback to help us continue to provide engaging content for all people affected by cancer. We would like to ask you to complete a brief survey that can 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 Blood Cancer United staff, please email, TheBloodline@BloodCancerUnited.org. We hope this podcast helped you today. Stay tuned for more information on the resources that Blood Cancer United has for you or your loved ones who have been affected by cancer.

Have you or a loved one been affected by blood cancer? Blood Cancer United 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 BloodCancerUnited.org/PatientSupport. You can find more information on financial assistance at BloodCancerUnited.org/finances, and insurance help can be found at BloodCancerUnited.org/insurance. These links and more that we talked about today will be found in the show notes or at TheBloodline.org. Thank you again for listening.

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