

THE BLOODLINE WITH LLS

A PODCAST FOR PATIENTS AND CAREGIVERS

Episode: 'Be Informed: Beneficial Medicare Changes'

Description:

Cancer related costs can be an overwhelming burden for patients on Medicare. However, new changes in Medicare will directly impact cancer patients and ease this financial burden.

In this episode, Brian Connell, the Vice President of Federal Affairs at LLS, discusses the new changes in Medicare for 2024 and 2025, as a result of the recent Inflation Reduction Act. Medicare recipients will benefit from these important changes, making cancer treatment more affordable and accessible.

Transcript:

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

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

Elissa: Today, we will be speaking about the recent Inflation Reduction Act and upcoming changes to Medicare with Brian Connell, the Vice President of Federal Affairs for The Leukemia & Lymphoma Society. For 16 years, Brian has secured legislative and regulatory changes that have expanded patient access to health care and made that care safer, more effective, and more sustainable. At LLS, Brian leads a team of federal lobbyists and policy professionals who advocate for meaningful reforms in federal policies to help blood cancer patients and their families. Welcome, Brian.

Brian Connell: Thanks. Excited to be here.

Elissa: Before we get into the Inflation Reduction Act and the effects it has on Medicare, let's start with the basics of Medicare for our listeners. Could you explain what Medicare is, how it works, and the different parts of it?

Brian: I appreciate the question. Medicare is a really complex program, and the one that's really important in terms of the ways that Americans access their health care. So, Medicare is an insurance program that is sponsored by the federal government that is the way that millions of people access their health care.

Typically, Americans over the age of 65, as well as folks who access Medicare through a disability, they use Medicare typically as their main source of health insurance; and so that covers everything from hospital visits to prescription drugs to a visit with your doctor. A really, really critical program that is the way that many Americans and many cancer patients access the care that they need.

Elissa: And what are the different parts of it?

Brian: There are four parts to Medicare. There's Part A, which is inpatient hospital visits. So, it's when you stay overnight in the hospital, sometimes for a night, sometimes for weeks. There's Part B, which is outpatient visits. That's when you go to the doctor. That doctor is located maybe in the clinic, maybe attached to a hospital. That's outpatient care, the care that you get, and you go home.

I'll skip to Part D before coming back to Part C because there's a little bit different. Part D is the prescription drug benefit. That's the type of drugs that you get from a pharmacy. It's drugs that you administer yourself. Part D is the program through which Medicare enrollees can access those types of drugs. Part C, also called Medicare Advantage, is essentially a whole separate program that replaces Part A and Part B for different patients.

Typically, you have patients who have Parts A, B, and D or they have Part C and Part D. So, a little complicated. Each one is really important though for making sure that patients have access to the right care that they need.

Elissa: As a younger person who is not on Medicare yet, I have always grown up thinking that Medicare is complete full coverage at no cost; and that is not the case, correct?

Brian: That's right. In fact, some folks can face enormous costs through their Medicare coverage, so there are some services that are covered in a better way than others in Medicare; but some really expose patients to enormous cost sharing, oftentimes due to the fact that the underlying care that's being provided costs a lot.

Elissa: I want to go back for just a second. You mentioned that people on Social Security Disability (SSD) might be eligible for Medicare. So, there are people on Social Security disability as a result of their cancer diagnosis who are under 65. What makes them eligible for Medicare?

Brian: Yeah. Due to that disability, as well as people who have end-stage renal disease, which may be something that someone has in addition to the cancer diagnosis, those are the two ways that Congress has set up, even though you're under 65, you're still allowed to access the Medicare program. And so, most of the people who are enrolled in Medicare are over 65, but those folks who are under 65, they're there due to that disability program or end-stage renal disease program.

Elissa: And they can get on that after two years being on Social Security Disability?

Brian: That's right.

Margie: Brian you mention the inflation Reduction ACT several times throughout this episode, but what is it? Obviously, it made some changes in Medicare.....which we'll discuss in a few moments, but how else will it reduce cost for Americans?

Brian: Yeah, it's a great question. The Inflation Reduction Act is a very long piece of legislation that Congress passed in 2022. And that made enormous changes to a whole host of federal programs. Things related to climate and taxes and other parts that we don't spend as much time working on at The Leukemia & Lymphoma Society;



but there are some health care provisions that are really important within the Inflation Reduction Act, some related to the cost for folks to access health insurance through insurance marketplaces, trying to lower the premiums for people to make it more affordable to access their insurance.

And then a lot of changes were made within Medicare. Some related to the price of prescription drugs and how those are negotiated and some related to how that prescription drug part of Medicare, how the Medicare Part D program works. What the benefit design looks like, when people pay for what and when. A lot of changes were made as a part of the Inflation Reduction Act to Medicare and particularly to Medicare Part D.

Elissa: Our podcast today is on those upcoming changes in Medicare as a result of the Inflation Reduction Act. Could you explain those changes, when they will be implemented and then why these changes are so needed.

Brian: Yeah, it's a great question. I'll take it in reverse order. The biggest struggle that we have heard at The Leukemia & Lymphoma Society for many years around access to prescription drug cancer care has been that many cancer patients are over the age of 65 or have gone into the Medicare program due to that disability before 65. About half of blood cancer patients are accessing the care that they need via Medicare.

And what we've heard from them is that when their drug is prescribed by their doctor, they go to the pharmacy counter, they try to use that Medicare Part D coverage to get that drug, and they are facing often \$15,000 plus in cost sharing for a single year of using that drug. And that first trip to the pharmacy, they're paying \$3,000 or more. There are a lot of people in the country that cannot afford that \$3,000 up front, let alone the full-year cost of that.

Elissa: Yeah.

Brian: There's a lot of blood cancer treatments that you're not just on it for a few weeks or even a year. You're on it for years. So, you have patients who may have a small nest egg. They may just be surviving on Social Security benefits, and there's no way they can put together the funds to make sure that they're able to stay on their cancer medications for that long. It's a real crisis.

We see that about 40% of cancer patients in the Medicare Part D program leave their drug at the counter when they go in and the cost is over \$2,000. Four out of every ten patients are leaving that drug at the counter. That's how we knew there was a problem. That's how we knew that we needed to change the way that Medicare Part D works so that people didn't face these enormous costs, so that's where the Inflation Reduction Act changes come in.

The area that we have been focusing on at The Leukemia & Lymphoma Society has been how do we cap those costs? \$15,000 a year, \$17,000 a year is obviously far too much. And one key component of the Inflation Reduction Act was a \$2,000 annual cap. So, starting in January 1 of 2025, no Medicare enrollee will be required to pay more than \$2,000 in that single year for all of the drugs they need in Medicare Part D.

Elissa: That's great.

Brian: So, it could be your drugs for blood cancer. It could be a whole host of things. But even with all those drugs combined, no one is going to have to pay more than \$2,000 for that drug. And we think that is really, really critical to make sure we end the era of \$15,000, \$17,000 a year for the drug. That said, that's not enough. We knew that just the annual cap isn't enough. We had to include what we call a smoothing provision. We had to make sure that no one faces that upfront cost of \$2,000 at the beginning of the year, because that's fine to say it's capped at \$2,000; but if you don't have \$2,000 and you can't get that drug, that doesn't really help you. What the Inflation Reduction Act did was, it said, "Yes, we're going to cap annual costs at \$2,000"; but patients are going to be able to spread those costs across the year.



You wouldn't have to pay more than, let's say, 1/12, one for each month, 1/12 of \$2,000. So, a patient can go to the pharmacy counter January 1 of 2025, pick up their blood cancer medication, and not only is their annual cost capped, but the cost for that trip to the pharmacy is capped at \$167. We know it's going to have an enormous impact on the people who got diagnosed, go to the pharmacy counter and would walk away from blood cancer drugs because it costs so much at one trip. Now that one-trip cost is capped under the Inflation Reduction Act.

Elissa: And smoothing also takes effect in 2025?

Brian: That's right. The annual cap and the smoothing of those costs over the course of 12 months, those provisions both start on January 1 of 2025.

Elissa: Is there anything happening next year in 2024?

Brian: Yeah, the beginnings of progress happen in 2024. Starting in January 2024, the program ends what was called the catastrophic phase of cost sharing, which was about what it felt like for patients. We had patients who "they were paying catastrophic," which was 5% of a drug's cost. But if your drug costs \$200,000 a year, 5% is a lot. We had patients paying \$700, \$900 even after they reached that phase where they're "only" paying 5%.

So, what happens on January 1 of 2024 is patients are able to go to the pharmacy counter, fill that drug, and never pay after that kind of trigger for the catastrophic program. We're still waiting on the exact number, what that means in terms of an annual cap. But, the projections right now is that would be an annual cap for patients of around \$3,000. It's a huge benefit for folks who had been paying \$10,000, \$15,000, etc. to have that capped at around \$3,000. But we don't have the smoothing provision. That's what happens in 2025. So we get part of the way there in 2024 with around a \$3,000 cap, and then all the way there in 2025 with that \$2,000 cap and smoothed across the year.

Elissa: Are there any other changes that Medicare patients need to know about?

Brian: There are a few and encourage folks to call the Information Resource Center at LLS if they have further questions on some of the details. There is an expansion of what they call the Low-Income Subsidy program which allows people to pay really small amounts for their drugs. If you qualify based on your income, as a senior or anyone else on Medicare, you could actually face \$10, \$15 copays instead of the high-cost sharing. That expansion of that program is happening in 2025 and a number of what we call back-end changes, how the program works for your Part D plan, how it works for the maker of your drug. There's a lot of changes on that side that are designed to decrease the cost of the program.

But the out-of-pocket cap, the smoothing of that over the course of time, the expansion of that Low-Income Subsidy program to really dramatically lower costs for folks of lower incomes, those are the things that are really most important and front of mind for blood cancer patients.

Margie: Wow, that's really interesting; and we appreciate the work that's being done for the patients. Now, do all Medicare patients benefit from these changes?

Brian: That's a really important point. Everyone will be eligible. No matter what plan you're in, there's a lot of choices of Part D plans. Seniors know this and folks who shop for Medicare, you open up the website and there's a lot of options. No matter what plan you're in, you'll have the option of the out-of-pocket cap, which is mandatory. The out-of-pocket cap will benefit everyone. You don't even have to think about it. It'll just be automatic. That's just built into what's happening at the pharmacy counter. You will face no more than \$2,000 in cost sharing starting in January 1, 2025.

The one thing where a patient has to act, a patient has to opt in to the chance to smooth those costs over the course of 12 months, so that is something that we are going to be encouraging every patient who thinks they might be able to benefit from



this to opt into that smoothing option with their Medicare Part D plan so that they have that in place on January 1. If they don't do that before the plan year starts, if they don't do that right at the end of the year or as they're choosing their plan in 2024, then there's the option to opt into smoothing whenever during the year that they think it might be helpful.

Elissa: Oh, that's good.

Brian: Yeah. We're working hard to make sure it's implemented in a way that people can do that at the point of sale. So, at the point where they're at the pharmacy counter, they see a \$2,000 number, and they say, "I can't afford that," that they're able to opt in at that moment to make sure that their costs at that trip on that day are limited by the smoothing provision.

Margie: Good to know.

Elissa: We've often seen that what happens in Medicare will affect private insurances as well. Is that the case here?

Brian: It's funny, it's almost the other way around. Medicare is finally catching up to what's been happening in a lot of what we see in commercial health insurance, where we've had an out-of-pocket cap. Ever since the Affordable Care Act, there's been a mandatory limit on the cost that you can face in a single year. So, we're seeing that now finally coming to Medicare Part D.

Patients are often surprised when they're 64, 63, they got a blood cancer diagnosis. They have enjoyed out-of-pocket cap on their drug costs; and then they go into the Medicare Part D program at 65, and they're shocked that they have no limit. This is migrating that really important patient protection that we've seen in the employer insurance market and the individual insurance market. That's now going to be a part of Medicare.



It's going to be much lower, so that's great. We'd love if this is something that we can push across the health insurance market to have lower out-of-pocket caps for drugs.

Elissa: Yeah.

Brian: The thing that is new that not a lot of places do, some states have reforms like this, but I think the smoothing provision, the ability for patients not to pay so much up front is something we're definitely hoping to get right in the Medicare program. To make sure it's implemented in the right way that actually really works for patients. And then once we have that, really trying to work on the commercial insurance side, the market for folks under 65 largely, trying to make sure that that works in Medicare and then, and make that work in commercial coverage too because we know patients could benefit from not having to pay so much up front.

Elissa: Oh, yeah, that's a huge thing. I can't imagine having to leave a cancer medication at the pharmacy because you can't afford \$2,000+ right off the bat. And so, that's just great.

Brian: Yeah, it's amazing. We've gone to Congress for almost ten years trying to push for these reforms arm in arm with blood cancer patients who will benefit; and, it's really a great moment to see that come to fruition and celebrate with those patients.

Margie: Well, Brian, you've really discussed some great changes that are coming. But the concern, I'm sure, for many Medicare patients are what can they do now, because 2025 is pretty far away?

Brian: I'm glad you asked because, it seems in some ways like we're just around the corner to 2024 and 2025; and in some ways it's eons away for folks who are struggling with the cost of their health care.

I'd encouraged folks to contact the Information Resource Center at LLS because every situation is different. Sometimes those costs are really high in the Medicare Part D program with a prescription drug. Sometimes those costs are high because you're



getting an inpatient treatment or need something like CAR T, which is done at the hospital and is infused and different than Part D drugs that are usually in pill form.

So, every situation is different, and the folks at the Information Resource Center at The Leukemia & Lymphoma Society can help folks understand what is happening in terms of where those costs are coming from and then hopefully be able to connect folks with the resources that might be most helpful for them. LLS has copay support programs. We also work with other nonprofits that have similar programs and can piece together some financial support for patients who are struggling now and can't afford to wait until 2024 or even 2025 for relief.

Elissa: I'm so glad that there are some possibilities for patients and options for patients right now that they can look to see where they might be able to find lower drug costs, they can get financial assistance through LLS. Other ways that they can keep paying for these really important drugs because it defeats the purpose, right, if we are doing all this amazing research and finding these incredible medications and treatments and they can't afford it.

Brian: That's right. It's a tragedy whenever we celebrate, a breakthrough drug coming to the market and then you have patients that, even if that drug is the perfect drug for them and really what they need, if they're not able to access it, what progress has really been made?

So, it's important, and that's why I'm proud to work at LLS. I'm proud of the work that LLS does to both push forward on innovation but also, work with patients to make sure that we're able to actually access those breakthroughs when they do happen.

Elissa: Yeah, absolutely. Our final question today. On our patient podcast homepage, we have a quote that says, "After diagnosis comes hope." What would you say to Medicare patients and their families to give them hope as they are faced with the costs of health care after a cancer diagnosis?



Brian: It can be hard when you hear that diagnosis. I mean it's hard for everyone, and it's scary. I think that you log into a website like LLS, you see that there has been a lot of progress, that there's therapies that might be really promising or that have proven to be really life-changing for patients. And yet you hear how daunting those out-of-pocket costs are.

I think that what's exciting is that there's hope just around the corner for patients who have been struggling for a long time. Maybe folks who are just diagnosed, but also patients who were diagnosed ten years ago and have been struggling with costs ever since. I think there's hope for all types of patients to know that once they hit 65 or if they're already there and in Medicare, that we are just months away from really eliminating this uncapped burden that folks have been worried about.

Like maybe even if you didn't have a diagnosis today, what if you got a diagnosis and what if you needed one of those drugs that you would have to pay \$15,000 to get? Those days are going to be over, and they're going to be over really soon; and we're really excited to be a part of that and make sure it works and to make sure that patients understand it and are able to take advantage of it so that they can access the care that they need.

Elissa: That's wonderful. Well, thank you so much, Brian, for joining us today and telling us all about these amazing changes. We are so excited to hear that the health care system is improving, at least for Medicare patients right now; and they will be able to eventually afford the cancer medications that are so important to all of us listening today. So, thank you so very much for joining us and telling us all about it.

Brian: Thank you. I appreciate you having me.

Elissa: 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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We would also like to know about you and how we can serve you better. This survey is completely anonymous, and no identifying information will be taken. However, if you would like to contact the 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. For information on financial assistance, please visit LLS.org/Finances. You can also find more information on how LLS is affecting state and federal public policy and join the advocate network at LLS.org/Advocacy. All of these links will be found in the Show Notes or at TheBloodline.org.

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