

Managing Financial Toxicity: Addressing the Hidden Costs of Cancer Care

National Webinar Transcript

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Presented by:



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Melissa Rosen:

Thank you so much for being here with us tonight, joining Sharsheret for an important conversation that honestly doesn't happen frequently enough. The financial cost of a cancer diagnosis and honestly, the conversation is equally important for those who are insured and uninsured, for those struggling financially and those who were comfortable before their diagnosis. So again, thank you for being here. As always, I have a few housekeeping items we'd like to share before we get started.

I want to thank our sponsors for today's program who enable us to continue to offer meaningful programs. So thank you to Daiichi Sankyo, GSK and the cooperative agreement DP24-0061 from the Centers for Disease Control and Prevention. And thank you to our partner on this website, the Patient Advocate Foundation.

This webinar is being recorded and will be posted on Sharsheret's website alongside a transcript. Participants' faces and names will not be in the recording. We have closed captioning available to display live captions on the bottom bar. Please click captions and then show captions. You also have the option to be anonymous during today's live webinar. You can turn off your camera and even change your Zoom name and there are instructions in the chat box now on how to make those changes if you wish to do so.

We've received so many good questions, really good questions through our registration process. But as questions arise tonight, please feel free to put them into the chat box and we will address them in the Q&A section at the end of the webinar. So as a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for more than 20 years because cancer is so much more than a physical experience. If you are interested in finding out more about Sharsheret's free, confidential, personalized services please email us or visit our website at [sharsheret.org](https://www.sharsheret.org).

Before we welcome our experts, we are so very fortunate to welcome Ellen, a Sharsheret program participant with her own very powerful story about the financial impact of cancer. So Ellen, thank you so much and welcome to the screen.

Ellen:

Thank you so much for having me. I really appreciate it. I came into Sharsheret's life through cancer, obviously, but it came at a point where you wouldn't necessarily think that we would be at our lowest. And let me give you just a little brief background. We were at a point where we didn't even know how to go about asking for help. Many people assume by when I say we were at our lowest, it would be during our first ovarian cancer in BRCA positive diagnosis in treatment, but for us, it was not. While cancer treatments were traumatic in itself, as many of us survivors know, what was more atrocious for us was the after effects that happened to our lives, which included me losing my job, the home that we owned, the vehicles, and even an affordable place to live in California. And I was a fourth generation Californian at that point, I might add.

The space in between from leaving one part of our life and family behind, mind you, we had to make very brute decision, to seek another it looks like a dryer spinning, if that makes sense, with clothes in it or a child's drawing with just a bunch of scribbles. Nothing made sense. Nothing seemed real. There was no new normal as we were being told. We were hitting brick wall after brick wall.

Fast-forward through this chaotic lifestyle with a whole bunch of horrible healthcare sprinkled in and living in three different states in our trailer, I might add, we had just about given up hope until Sharsheret came into our lives. No other program would hear us. I don't know if that makes sense, but hear us, hear our story, hear where we were. We weren't just what we were on a

piece of paper from our tax returns the year before, which every other place and program seemed to care about.

Sharsheret took the time to hear us. If it wasn't for the very first phone call that I had with a lovely lady named Erin, which inevitably led me through Symone and The Chain Reaction opportunity, we would not have been settled into a new state here in Charlotte, North Carolina with job opportunities for my husband, excellent healthcare for myself and an affordable house to rent.

Do we miss our home in San Diego that we left behind and that we owned? Absolutely. But after everything we have been through, we are eternally grateful. We didn't know and still don't know how to thank Sharsheret and the chain reaction enough for the help that was provided.

Specifically, what they did was they heard about us, they heard our story, they heard that we didn't have... We had enough money to eat and to pay for gas for our truck and to find places to rent for our trailer, but we didn't have enough money to save up for a down to rent a house. They heard that part of our story. They heard the almost desperation in our voices at that point, and we both, my husband and I, felt seen and we are eternally grateful for being seen because if it wasn't for that opportunity, we wouldn't be here.

That was back in 2022. And now we have been settled here. I have gone through an entire recurrence, but I've had excellent healthcare here. We can actually say that we are living somewhere now. And if it wasn't for this gracious, gracious opportunity, we wouldn't be where we are today. Nothing prepares the family for the destructive diagnosis of cancer, nothing, but Sharsheret sure has proven to be there to pick us up and to help us pick up the pieces. And I just personally and my husband and my daughter, we thank you from the bottom of our hearts for all that you have done and to help us get out of that spin cycle after ovarian cancer. So that's just I wanted to express my thanks.

Melissa Rosen:

Ellen, thank you so much for sharing your story. It's really an example of how somebody who is doing fine, who is financially secure can really be felled by the expenses related to a cancer diagnosis. And I really believe it is so helpful to hear other stories as we're going through something challenging ourselves. So thank you.

As we move into the main presentations, I also want to remind you that Sharsheret is a national not-for-profit cancer-supporting education organization and does not provide any medical or financial advice. Always seek the advice of a qualified health provider or financial advisor with any specific questions you may have.

We are so very fortunate to have two amazing speakers with us today. Our first speaker is Dr. Maggie Liang. Dr. Liang is an associate professor in the Division of Gynecologic Oncology within the Department of Obstetrics and Gynecology at Cedars-Sinai Medical Center in Los Angeles. She completed medical school and obstetrics and gynecology residency at the Ohio State University and subsequently, she graduated from the Cedars-Sinai and UCLA combined gynecologic oncology fellowship.

During that time, she also obtained her master's in science and health policy and management from UCLA. Her research interest is in developing multi-level interventions to address the financial hardship that cancer patients and their caregivers face during treatment. Welcome and thank you so much for being here with us today. The floor is yours.

Dr. Maggie Liang:

Thank you so much for having me. And Ellen, I want to echo that. I really appreciate you sharing your personal story and I can see how powerful the community around Sharsheret is, so thank you. I'm going to share my screen.

Okay, so today my goal is to talk a little bit about from a healthcare provider perspective, and I'm also a researcher, how we're thinking about this problem and trying to think of solutions. It's not going to be a one fit solution. It's a pretty complicated problem, the financial burden of cancer care. But again, just to shed light on what is going on and would love to hear any questions or feedback at the Q&A.

I do have some research funding which is listed here in consulting, but they're unrelated to the talk. Okay, so there's this term financial toxicity, and just to make sure we're all on the same page, medical oncologists actually a little over a decade ago, Dr. Yousef Zafar who was in Duke University coined this term within the healthcare research literature. So just like toxicity is the term we use for side effects of treatment, so just like hair loss or nausea or vomiting or fatigue may be a side effect of treatment, the distress or hardship arising from the financial burden of cancer treatment, actually we should think about as a side effect of treatment. And just like we counsel patients on the other side effects and help them manage these, that's why this term was coined to build awareness and start to more systematically develop solutions.

On the right here, I pulled just a New York Times editorial. It's from 2019, but Susan Gubar did have ovarian cancer herself. But you can see this headline here, I just think echoes what Ellen shared with us. So while medicine transforms cancer into a chronic disease with which patients can live for an extended period of time, financial toxicity threatens to turn chronic too. And you can see here in the palm, there's a house and a car and all the medications patients have to also think about paying for both for cancer treatment or even side effects.

So when we think about cost of care, there's two main categories we can think of. So it is direct out-of-pocket costs. So these could be, so that's on the left, out-of-pocket costs for things like your provider visits or labs or imaging, medications and supplies. There's also nonmedical costs that are still required in order to adhere or undergo treatment. So transportation to and from where you may be receiving treatment or patients may be receiving treatment, parking and lodging, which really can add up.

And then on the right the other way, we can think of costs actually is the time cost. So what would someone be doing if they weren't spending all this time dealing with their cancer treatment and their cancer symptoms and any side effects. So that might be working for an income, going to school, taking care of children or older individuals or spending time with loved ones, which we know is really important and meaningful.

So this is a figure from the National Cancer Institute that shows that there is a link between health and financial outcomes. So if you start here on the left, you can see the individual will have their pre-illness health, whatever assets, debt and income they have, and then if you move to the right, they experience illness or injury. So in this example, cancer, they may or may not have medical insurance and then they are going to decide on their treatment.

And so they're going to face medical costs, which we talked about at both medical and nonmedical costs. And this over time especially can impact people regardless of their insurance status and regardless of their pre-existing financial status. So it can cause financial strain and distress. And so we do know that there is actually evidence in the research world that higher out-of-pocket costs or more financial strain on cancer patients is associating with delaying care and more difficulty adhering to treatment due to difficulty affording care. There are two studies actually that show an association with those who have very severe financial strain. So bankruptcy as a form of severe financial strain actually having worse cancer mortality. So this is

really important and really is linked also to health outcomes as well as you can imagine someone's financial and their assets again that they can even pass on to their family or children. So when we think about financial toxicity, there's three domains that are described. So taking you through each of these. So in the green circle there's the psychological response that someone may have. So this is the distress or worry or even sometimes patients describe shame related to having to deal with this when they maybe weren't otherwise dealing with as much financial strain previously. There's an impact on material conditions. So these are things like the actual out-of-pocket expenses, losing income maybe because of not being able to work. And this can also impact caregivers who are often helping patients get through their treatment. Medical debt and then again in a severe form, bankruptcy. And then in the orange circle is the impact that not being able to afford care may have on delaying or missing care or not adhering to treatment. So you'll hear reports of patients who are on an expensive cancer pill maybe thinking I'm going to take the pill every other day because I can't really afford the cost of it, taking it every day.

Just to provide some illustrative examples, although Ellen again shared a really personal experience here. So we did interviews, my group, with ovarian cancer patients and these exemplify the issues I just said. So I'm not going to read the whole thing, but one patient for the psychological response, which was the distress related to this stated, "I sat in fear of answering the telephone and someone being sent to my door saying that I owe this money." And now they felt ashamed when really they had a lot of pride previously of being able to pay their bills.

Material conditions, someone shared, "We depleted everything at that. We've sold everything and it's kind of sad." Interestingly, in this group it was about 15 patients we interviewed. Most of them really said the most important thing was trying to get the care that I could and almost saying I was stressed about the cost, but I just got to put on the back burner because there was so much other things that were overwhelming me. So you can see that long term that can cause a reactive waiting until there's a true, even more severe crisis before knowing where to turn for help.

These are broad suggestions, but so what can healthcare teams do and what can patients and caregivers do? And then I'll share some research that's being done just so everyone's aware.

So healthcare teams. So there's a growing awareness in oncology, which is really important. So we really need to screen all patients for these issues. And there are different screening questions that can be used in practice to remove the stigma of asking this question. And really to make patients understand that if we screen the goal is to actually help patients connect to potential resources and remove the fear that a patient may or may not have about, okay, if I can't afford care, maybe I'm going to get suboptimal care as an example.

Identifying patients who are at risk for developing financial toxicity over time or in the future. Providing estimated cost of care clearly could help. But this can be difficult because there is a lack of transparency from insurance companies. Educating patients and their caregivers to really give them more knowledge and skills related to how to navigate, for instance, insurance or talking to employers, maximizing benefits like family medical leave, disability if that's appropriate. Linking patients to resources, really important. I think Ellen mentioned maybe not knowing initially where to turn or some maybe potential red tape related to getting the financial assistance or resources that patients need. And healthcare teams really need to be a partner in this with patients.

What can patients and caregivers do? So it's a similar thing where we want to build awareness and then also empower patients to talk to someone on their care team without fear of stigma or shame. Also making sure patients and caregivers know what questions to ask. Learn more about insurance coverage because I do think there's some statistics that a survey showed that 8

in 10 patients reported having some sort of difficulty with their insurance coverage, not covering what they thought it would or having delays or due to authorization, things like that. So again, giving patients or their caregivers the skills to help navigate that, help them keep the receipts bills and keep track of costs, budget. Clearly, community such as Sharsheret and other community cancer awareness or support groups or maybe it's other social groups, church groups, hobby groups. If we talk more openly about these issues, we can troubleshoot and learn from each other. And similarly, becoming a patient advocate.

Okay. So we know that this is a complicated problem, so we need to intervene at the individual, interpersonal which is, for instance, the provider and healthcare team or maybe even employer level. Organizational is like the health system, employer level. Community, community organizations, which here, this whole group knows how important that is. And then clearly state and national level policies and also insurance companies are important stakeholders in this problem.

So at the individual level, we talked about giving patients the information and skills that they may need. Interpersonally, we can talk more proactively about this issue and help link patients. Also, if we better manage patient's symptoms, maybe they can potentially work part-time or have work accommodations if that's feasible.

Organizational is having financial navigation is what it's called where there's formal system for screening and linking patients to resources. And again, employers maximizing work accommodations. Often, we do rely on community organizations. Patient Advocate Foundation is a great example to help patients find potential resources. And then expanding insurance coverage for those who are uninsured, decreasing the amount that patients have to pay, limiting drug costs which really are soaring. And then worker protections, so like job security and retention or being able to keep your insurance.

I'm just going to go through a handful of examples. One thing that I'm working on, this is an old version, but I don't have a nice graphic design example yet, but we are working on a booklet and training a lay educator that could maybe be part of a healthcare team using to teach people about health insurance terms, understanding medical bills, employment questions to ask your doctor or employer if you or your employer are employed and how to maximize things like disability, ask for work accommodations, things like that. So we're working on this sort of educational intervention and have really involved a lot of patients and caregivers and healthcare team members including social workers, et cetera, and developing this. So this is one example of something that can be done and will actually, hopefully be doing a research study here at Cedars and at my former institution, University of Alabama at Birmingham to evaluate this and get more feedback from patients trying to use it.

This is an interesting one by Dr. Lauren Hamel, who's in Michigan, in Detroit, I believe. So she and her group have developed a DISCO app, which is currently being studied. So they created an educational video and then an application for a smartphone where you enter your employment and insurance status and indicate any financial concerns. And then based on that, the patient then receives a tailored question prompt list that they get printed out in the clinic and then are asked to discuss these with their oncologist and maybe other care team members that may be appropriate like a social worker.

So they're testing this in patients with breast, lung, colon and prostate cancer, and it's a randomized trial, so flip of a coin. So half are getting usual care, so whatever exists now or third. A third are getting the app and using it with their oncologist the second time they meet with them. And then the third one is they use the app, but then also two months later they get an email or text reminder reminding them about resources and other questions to ask.

So in this study they're looking at, they're actually going to record the oncologist visit to see if there's more discussions about costs because of this facilitated form or worksheet that's personalized to the patient. If more people who use the app get more referrals for support, if they have more or less financial toxicity sign, if they adhere to treatment better. Another example, which is another app is this app that was developed at Memorial Sloan Kettering by Victoria Blinder and her team. They're testing it in breast cancer patients and it has tools that patients can use to help better track and manage their symptoms with their oncologist, again to maximize their ability to work if it's feasible, maybe even part-time. And then the other part actually is a coach to negotiate or talk to the employer about work accommodations.

And so this is a randomized trial, so flip of a coin. Half gets what's existing. I think they get a paper booklet and that's more general and then half use the app and they're looking at if that helps more patients work or return to work after treatment completion.

One other thing that's being studied, I'm just showing this example, is financial navigation. So that's screening everyone for financial hardship. So we did a pilot at my former institution, so we screened every patient, so I'm a gynecologist, so patients with gynecologic cancers who were starting treatment. Just everyone was screened for financial hardship and one in four screened positive. And here on the right, you can see what types of needs people had. So the highest needs were insurance or medical bills, upfront medical payments and utilities followed by transportation. That's the blue bars.

In the green bars, you can see that actually still 20% of people who didn't have financial hardship using the screener that we use. They actually still reported a financial need. So again, it is sort of regardless, but clearly, it's more severe in people who were experiencing financial hardship. So this is a first step in identifying who can benefit from health.

And then this other one just briefly is actually philanthropically funded, but actually patients who are low income who are diagnosed with cancer are going to be given a \$1,000 per month stipend to see, and they can use it on whatever they see fit and they're going to follow actually adherence, financial toxicity, anxiety, depression, food and housing security, and then eventually mortality. So that's pretty novel.

And then I think this is my last example. This one is just demonstrating the importance of financial partnership. So this one, they partnered with Patient Advocate Foundation, who's here today, who had a case manager and then who would help patients monthly and then CENTS which had financial counselors who could talk about budgeting and retirement and then they did a financial literacy course. So about 60% of patients did at least one out of three of the things, and it did decrease anxiety about cost by about a third, although financial burden in the short period of time didn't change. So they're actually continuing to work on this intervention.

So really, in conclusion, one in four patients experience financial toxicity. It's both money and time and it definitely has an impact on patient's financial status, quality of life and health outcomes. And really this is an important part of comprehensive cancer care and we're really going to have to have multiple stakeholders. Lastly, this is just from that educational book that we're developing. This is some of the patient resources that are specific about dealing with financial and work considerations. So we can share this after the talk, but I just wanted to share this here in some great organizations that have information on this.

Melissa Rosen:

Thank you so much, Dr. Liang. I found myself nodding a lot. A lot of it resonated and felt so relevant, so we're so grateful and you're going to stick around because we have some Q&A coming. But our next speaker, our next speaker is Courtney Jones. Courtney joined the Patient Advocate Foundation in 2004. In her current role as senior director of case management, she

provides oversight on the daily operations of the case management division and the partner support services working to ensure their services impact the lives of patients nationwide. Welcome Courtney and thank you and the Patient Advocate Foundation for partnering with Sharsheret on this webinar.

Courtney Jones:

Thank you very much. I appreciate the opportunity to be here and talk about our services and the financial toxicity that patients are facing. Let me share my screen. Let's see. Yep.

Okay, so let me start by saying I'm Courtney Jones with Patient Advocate Foundation. I appreciate the opportunity to be here. The term financial toxicity describes both the practical and emotional impact from the cost of care on individuals and families managing a cancer diagnosis. So during my talk here, I will hopefully try to explain the factors that contribute to financial toxicity, explore their impact and provide ways to reduce or overcome these obstacles. And then we'll spend some time talking about useful resources to assist in everyday bills, managing costs and eliminating barriers.

So just to talk a little bit about Patient Advocate Foundation, we are a national 501(c)3 non-profit organization that provides direct case management and another coined term that you hear often is navigation services to patients with chronic life-threatening and debilitating illnesses. Our mantra is to help one patient at a time to overcome a range of access barriers and help them focus on getting and staying well. We've been an organization for almost 30 years that have been founded on sustained case management services and have broadened our scope to have some direct financial assistance to patients as well.

So when I get into who we are and how we help, we have a very broad reach. As I stated previously, we are a national organization and this is just some of our statistics from 2023. And it's very interesting to note that 5 of our 10 issues are related to disability, health insurance, out-of-pocket medical costs, as well as general cost of living. We have served over 16,000 patients. And out of those patients, 87% of them are insured, which is very interesting when we start talking about medical debt. Talking about the reach of case management and the needs of patients, we do have what we call a patient insight institute that is a research arm of our organization that they did a micro-survey back in 2023 focusing on two things, the administrative tasks that fall on patients and their caregivers or loved ones and then the impact that that has on patients.

So when we're looking at that, it was interesting to know that a lot of the administrative tasks, how we coin it are falling to patients to fill out applications, complete some calls and follow up paperwork to do the research and the due diligence to find resources or to make that connection to see what assistance is available. So that is a lot for patients or family caregivers and loved ones to have to juggle while also trying to concentrate on treatment and medications. And then you've got that coupled with the struggle or the inability to pay for the essential costs and necessities like food, transportation, shelter, time away from work and the loss of that income. And these issues are getting tougher and tougher to solve so these were just interesting to note that 64% of the participants of the survey stated that they are someone that has provided care or experienced this administrative burden resulting from a medical diagnosis. And out of those, excuse me, 20% spent time on what we call safety net applications. And then 55% of their time were spent on just health insurance administrative tasks.

So when we talk about case management, what does that mean and what does it mean at Patient Advocate Foundation? So we provide one-on-one intervention support, our case managers directly intervene on patients' behalf making a lot of conference calls, taking this administrative burden or lifting that administrative burden for patients. So we are here to help so that patients can focus on the care that they've been prescribed and not worry about these other

tasks at hand. But we also help patients understand how to utilize their existing benefits. I know a lot of patients say, I have insurance, but I'm not sure what that cost of care is going to look like or what's going to be covered. So we help them understand navigating what benefits they have and maximizing the coverage that they have. That's talking about network coverage, in network, out of network. And then we also help improve understanding the utility of resources that improve their ability to manage the cost of care.

Again, insurance benefit design, what disability options are available either through their employer or through social security disability and other safety net and charitable programs, helping them look at them, reducing their medical out-of-pocket costs, finding and locating those resources to support those financial costs as well as cost of living experiences ... expenses, excuse me. So in the next couple slides I hope to explain what insurance challenges may arise and what to do. And then opportunities to manage medical debt and what that means. When I talk about patients approaching, or excuse me, case managers approaching a case and removing barriers for patients, we like to go down this path. So there are several different areas that we talk with patients and caregivers on and it's important to even have that conversation now because you can kind of see how they lead down this path and all kind of intertwine.

So the first is insurance access. Do they have a lack of insurance? Is there a high out-of-pocket requirement and what does that mean? What would that financial cost look like? Then that leads to potential medical debt and the ability to pay. So now that they have this insurance access and are utilizing their benefits, what is that cost going to be to them and do they have upfront costs before they can get treatment? Are they in ... have inability to obtain prescribed medication at the pharmacy because of the cost? So we talk about and resources that are available. Going further down the path, once they have a diagnosis and are starting their treatment, are they able to continue with employment, and what does that look like? What employment protections are in place and what benefits do they have through their employer to be able to tap into and access. Or if they're unable to continue employment, what does that look like with short-term or long-term disability options or looking at social security disability or taking just a family medical leave at, time away to continue with treatment.

And then if you're unable to continue with treatment and your pay declines because of your lack of hours being able to work, that's going to have a cost or could have a cost of living impact. So what does that look like? What resources are there available? Let's proactively try to have that talk so that there's not these stress levels that come, when and if that comes up. And that leads to my last. As you've gone down this path, a lot of that leads to the emotional distress. These financial concerns and medical cost of care concerns can impact a patient's ability to access and afford the care and that brings that stress. And then we have to try to look at areas to lower the stress while improving the financial concerns that they have so they can focus on their care. Common questions that get asked throughout treatment. I like to throw out there is, can someone help me plan my budget? What will my treatment cost? How much will my co-pays be? Are payment plans an option?

How often will I need these scans or lab testing that will incur a cost at each time and will that be covered by my insurance if my insurance does not cover fully my treatment, what are my other options? And where can I find help with transportation, housing, or other cancer related costs as they all are going to intertwine? So I do like to talk a little bit about insurance terms and what that means. We get this commonly through our phone lines with just understanding what does it mean by deductible co-insurance, co-pay out of pocket maximum. These are words that often get told to patients at either their medical visits when they're talking about cost of care or when they're looking at their coverage or contacting their insurance company, excuse me.

But a deductible is what a patient is responsible for before the insurance plan will cover a cost. So that can be varied for individuals and not all plans are similar in these costs, but that is the

financial cost that a patient will have to incur and pay prior to the insurance starting to pay. A co-insurance is a share of cost and I always say it's a percentage of costs that you as a patient would hold the financial responsibility for. A common calculation is 20% of the care. So your insurance company will pay 80, you pay 20% of the care. A copay is a set figure, so that is a predetermined amount such as \$20 that you would pay when you go to the doctors. And you can have different copays for different providers. You can have a \$20 copay for your primary care provider and a \$50 copay for your specialist, \$150 hospital ER copay. And then of course you're going to incur lab costs, which are typically co-insurance costs.

Then we have out-of-pocket maximum. That's the maximum amount that the plan will require the patient to pay for their healthcare services that year. Typically, the copays, co-insurance and deductibles all apply to this out-of-pocket maximum. And once the out-of-pocket maximum is reached, the insurance pays a 100% of the medical cost for that remainder of that coverage year. So it's important to know what your out-of-pocket maximums are. And typically when you get an explanation of benefits, it will have where you are and where you've met your deductible or where you are and how much you've met of your out-of-pocket maximums. So reviewing your policy and your explanation of benefits is important to understand the cost of care. The next comes insurance denials and appeals. There's many different reasons for denials and understanding what those reasons are. It could be billing paperwork had incorrect codes. Your name was spelled incorrect, the date of birth was incorrect.

These are what I call administrative burdens where it's trying just to get everything coordinated and corrected to be rebuilt. Then you can get the actual denial of the claim that says it was not medically necessary or there was a failure to obtain a pre-approval. There's a couple others here but not a covered benefit. That's another one we see quite often. What does that mean? That means it was denied and they're not going to pay the claim that was submitted. However, there are appeal rights. And I would encourage every patient that receives a denial to speak to their provider on the appeal. And filing the appeal, and whether or not the medical facility is going to help facilitate that appeal or if you would like to go outside and seek the services of a case manager or navigator to assist with that appeal. Our case managers at Patient Advocate Foundation do this regularly and assist patients through all the appeals process.

There's three different types of appeal. There's a pre-authorization appeal that is prior to the services received. There's a post-treatment appeal that is for denial of care that has already been received, and there's an urgent or expedited appeal that you could immediately ask for a review if delay in treatment would seriously jeopardize the life or overall health of said patient. There's timelines associated with these appeals. So these slides should be available and hopefully you can understand and look at some of this information to see the timelines for decisions or timelines to submit appeals as well as timelines for decisions. We kind of talked about reasons for denials, but there's multiple levels of denials as well. So you have phase 1, which is your denial of coverage, and then you can go and appeal and that goes into an internal appeal to the health insurance company. So they take another look at this based on additional information that you've submitted and have another review.

Your physician can also ask for what's called a peer-to-peer review, where the physician calls the physician at the insurance company that is reviewing the appeal, and they have a conversation about the care. Then if you need to go to the next level appeal, that's an external appeal and that is where it goes to an outside independent review organization that then takes all information submitted and has independent determination. When we talk about prescription drug assistance, there's multiple programs because cost of care and prescriptions are becoming higher and more out-of-pocket costs that are now shifting over to the patient. So I often like to talk about the different options available. One is the pharmaceutical assistance programs. Many pharma companies and specialty pharmacies have these assistance programs that can help

patients cope with the financial aspects of the diagnosis. They can help in many different ways. There can be a copay card or copay assistance that they provide or they could cover the prescription costs or prescription at no cost, excuse me, to those without health insurance or without prescription coverage.

Excuse me. In addition to those assistance, they sometimes offer free trial vouchers. They also have case managers and navigators that can help go through the process of prior auth and benefit reviews, determine what your coverage is. There's one-on-one support with mentors and healthcare professionals to understand what that impact of that medication may have. They can provide sample billing and coding information to help with appeals. They also, their case managers there can help with denials and appeals and then they often refer out to appropriate other assistance options, which we'll talk about a little bit later as well. This is just telling you there's applications and you can find these applications for these assistance programs typically online by Googling and looking up that medication. And then they also have a toll-free number that you can call and speak to somebody to ask what the options are that are available based on your financial needs that you may have or just that the medication has been denied and you now need access to prescribed medication.

They all have different eligibility requirements, so not one manufacturer assistance program is the same. So I would always encourage for every medication to go and do that research or speak to a case manager that can help you do that research and make those applications. There's also charitable organizations. We are one of them. We have a copay relief organization that has a financial assistance program that can, if you qualify for eligibility criteria and we have funds available for one of our covered diagnoses, then you may qualify to have the prescription copays covered by this charitable organization. Some also assist with traveling for treatment such as transportation and lodging. There are some financial charitable organizations that help with caregiver expenses including direct payments to some caregivers. There's also others that help with health insurance premiums. I listed a few of them here and this information, again, will be shared. So these are just some that we use on a regular basis here at Patient Advocate Foundation when helping patients try to find some financial assistance through these organizations.

There's also drug discount cards, which I had mentioned previously as well, but there's some common drug discount programs. I know a good common one that I know people have heard is GoodRX. Then there's some others, but they offer reduced costs on some medications, so that is outside of your insurance. However, if there's a financial constraint, this may be the avenue to access that prescribed care. Medical debt, what do you do? So gather and review all medical bills, collect them all, review them against the insurance statements or explanation of benefits, EOBs, they're all called something different depending on who you talk to. And then review those bills for accuracy, ensuring that the charges are correct and services were rendered. So an example, comparing the hospital bill against the explanation of benefit can reveal any discrepancies from billing or incorrect charges or unprocessed claims. The other thing is charity care financial assistance offered through hospitals or financial institutions. So medical facilities have these programs and have eligibility criteria.

However, I always encourage you to talk to the financial advisor or financial department at the hospital or the medical facility to see that you can apply and what that criteria is. These are the five steps that I often line out ... lay out is check the eligibility guidelines, fill out the application, make sure to send the application in, follow up on that decision and if needed, appeal the hospital's decision. You can also appeal that if they're looking at a tax return from last year and your financial situation has drastically changed, that is a reason to go and ask them to re-review and to look at it with your current income. So I kind of just like to put this all in a case

perspective. So here's Mira. She's a 37-year-old who lived with her husband in the city. Her and her husband, excuse me, are adoptive parents to a 4-year-old boy.

Their financial situation, she's a graphic designer. She works for a large nonprofit organization. She has what we call a high deductible health plan through her employer. So that means she has a high deductible, sometimes 5 to \$10,000 before her insurance will cover anything. She was diagnosed with stage 2 ductal carcinoma and then has seasonal allergies. So she underwent a lumpectomy and is now beginning oral chemo. The cost of the oral chemo, excuse me, along with the medical expenses, has become a substantial financial strain on her and her family. Some of this may be common to you all, and you've heard this multiple times from either yourself, loved ones or those within the community. So steps that the case manager would take or that we encourage patients to take is what we've already spoken about, charitable co-pay programs. Are there programs that she could help with the cost of these chemo care?

Is there a manufacturer copay card that she can apply for that would reduce that cost and lower her out of pocket. Discuss with the doctor? Sometimes the doctors can provide equally effective but less expensive alternatives. It's always important to have that conversation with your medical care team and talk about those concerns. Work with navigators, work with social workers to find these resources. Negotiate if you have a bill that you can't pay, maybe you're able to negotiate a discount or payment plan with a treating provider or facility. Again, check for financial assistance at the hospitals, which is what we spoke about earlier. Some companies employees offer health savings accounts that you can contribute to pre-tax dollars and sometimes your employer will match some of that. So that helps you build a savings of income, excuse me, that you can use to help pay for your healthcare costs.

And then it's always important to review your plan options. So during open enrollment, review your insurance options, make sure that you have the right coverage for you. Make sure that your medications are covered, your facilities that you wish to go to are in network and if not, what other options are there available through insurance that you can maybe change? Is there one that has a lower deductible that better fits your financial situation? We have a plethora of education information in our education resource library. It has many different areas of full length publications. We have quick snippets of information or just pamphlets. And then we have a lot of webinars. So I encourage everybody to visit our education resource library and familiarize yourself with all the resources that are available. Anything from insurance disability, appealing, a health insurance denial, medical bill management. It really breaks it down. And then we have the National Financial Resource Directory, which is over here that there's a QR code.

That is our number one utilized resource directory. Our case managers utilize it as well. It is on our website. It's a searchable database of national, state and local financial assistance programs that can help with medical and nonmedical expenses. We rebuilt and launched this search tool in May that has a lot of enhanced features. There's also a tutorial on how to use the tool. It provides a wealth of resources that then leads you over to what their eligibility criteria is and how to apply. So that is a great tool for not only you as patients or caregivers, but also social workers and navigators that are out in the hospital or medical facilities.

And then of course I give our resources. So our website is patientadvocate.org. And then our phone number for our case management services. We also have a copay relief program and our financial aid funds that are broke out as on here as well. And then our link to our financial resource directory and education library. So I wanted to take the opportunity to thank you all for allowing me to present this information. I know it was a lot, but I'm hopeful that it will allow you to better understand that you're not alone and there's a lot of help out there. And please reach out as there are many different organizations that are willing and ready to assist with whatever questions or areas of support that you are seeking. Thank you.

Melissa Rosen:

Thank you so much. So much information, I'm going to ask for you to unshare your screen and we are going, to ... we've brought Dr. Liang back up as well. And we got a lot of great questions and so we're going to take a few minutes to answer them. So first of all, let's start With ... let's start with how ... can you discuss how to budget as a cancer patient or a survivor? You've been diagnosed, you already know this is part of your expenses, certainly in the immediate future, but likely in the long-term future too. What can one do to help prepare for the oncoming expenses?

Courtney Jones:

Well, I can start there then I'll let Dr. Liang expand if there's anything else. But I often encourage patients, and I know I said it in my presentation, to understand your insurance for one, to understand what that deductible is, what your out-of-pocket maximums are, and try to get a grasp of what that financial cost could be. Sometimes again, it's having that conversation with your medical care team of what your treatment plan will look like. And some hospitals have some financial navigators available that can help have this conversation. But I think it's important to know that cost of care, to know what that's going to look like. And if there's going to be a financial impact to, if you know ahead of time sometimes that don't always know if there's going to be a financial impact to your employment.

And try to plan for that. Or what benefits you have available. I know I often say you don't know what you don't know, and you have benefits that are available through your employer, but you've never had to access them. So sometimes they're just sitting back here and you're not thinking about them. So really understanding what that coverage is available, short-term, long-term disability, what your sick leave looks like in those areas.

Melissa Rosen:

Okay, thank you. Dr. Liang. Actually, this question I think might be for you. Somebody asked, what is the best way to address the disconnect between the doctor, the hospital and the insurance company, all of these things that come up when something's coded wrong or things like that. From a systematic or systemic, I would say point of view, what's being done to try and fix these things?

Dr. Maggie Liang:

Yeah, I mean, I think to the point of whoever asked the question, it is a very complicated system. I can tell you firsthand as a provider. Clearly, providers have lots of administrative staff to help with this, but it's still not very transparent ahead of time, to be honest. I do think, I mean there are a few policy things because clearly that is how there may be broader impact in a positive direction. So an example is, I'll just use an example like the No Surprises Act actually that was passed a few years ago. So a patient, I think it's like 30 to 50%. They took the nine most common surgeries that were performed, and it's like 30 to 50% of individuals across the country going to have a surgery with a surgeon that they think is in-network. So covered by their insurance actually got a surprise bill from someone like an anesthesiologist or maybe the pathology or the lab or something that was out of network and the patient would never have been able to know.

So I mean, again, this is just a small piece that will help the underlying problem,

Melissa Rosen:

Right, of course.

Dr. Maggie Liang:

But really for emergency services, they kind of made it so that even if you're taken somewhere that's out of network, that they can only charge you a network and that there's a way to appeal. I mean, I think some of the challenges right now is you can hear a lot of the band aid/solutions that we have these days have a lot of administrative burden like the forms to fill out, tax documents to provide in order to show you're eligible. So I think that is something honestly, that somehow I don't have the solution unfortunately, but could actually relieve a lot of stress, basically. So I don't have the solution, but I'm just providing you know -

Melissa Rosen:

Yeah, no, I understand. I think it's helpful and hopeful to know that there are people working on some of these solutions. Listen, our timing is such that we were supposed to end right about now, so I want to actually officially conclude with some information that's very important for people who do have to get off. But if anybody wants to stay on, we have several more questions. Dr. Liang has generously agreed to stay on for a few extra minutes. Courtney, I'm hoping you can do the same as well. But for those who can't stay on, I just want to thank you all for being here. Thank you to Ellen for sharing her story and to Courtney, Dr. Liang. Also, the Patient Advocate Foundation for sharing your passion and your expertise. Thank you to our sponsors, Daiichi Sankyo, GSK, and the Cooperative agreement DP-24-0061 from the CDC.

We are putting link to an evaluation in the chatbox right now. Very brief, very important because we really do take what you say into account. So one of my colleagues is going to put that directly into the ... oh, I see. It was there called SurveyMonkey. And I want to remind you that Sharsheret has many resources available to help you. Sharsheret has a great deal of information on our website, a whole section on cancer, insurance, and finances. That link is going into the chat right now. And included on that page, along with many other things are information about our need-based subsidies for certain nonmedical expenses through our BFF 2.0 Program which includes the purchase and styling of human hair wigs, microblading for eyebrows, nipple and areola tattooing and scalp pulling. Each of these have quarterly grant cycles. So the best way to find out what's currently available is to connect with your local Sharsheret social worker or email our clinical team. And that email address is in the chatbox right now.

We also offer urgent funding through our partnership with change reaction for those who are facing metastatic breast cancer or advanced ovarian. There are also some broader applications through Change Reaction and potentially some additional availability for that kind of urgent funding for those who live within California. And information on all those programs can be found on that link. Okay. We're going to go back to some of the questions now, and I thank you all for your patience. Okay. A lot of questions about not qualifying for things, for assistance because someone has private insurance or not qualifying for other things because again, they don't have Medicaid, they don't had ... they haven't had that need expressed, but, but they are still well below, making well below what they need to cover all of their costs.

Courtney Jones:

Yeah, there's a lot of programs that have varying eligibility criteria. You're going to find that across the whole landscape of different organizations or different pharma assistance programs. There are ways to navigate some of that. Not all always with eligibility criteria. There are some, again, co-pay assistance programs. I'll mention specifically that only assist for commercially insured and there's others that are just specific to Medicare insured for costs. And then there's the pharmaceutical assistance programs that again have different eligibility criteria. Some FPL comes in to play on some, some others-

Melissa Rosen:

And for those who aren't aware, FPL, could you please?

Courtney Jones:

Yeah. Federal poverty level. Sorry, it's my acronyms.

Melissa Rosen:

No, no, I know. And several people use the acronym when making questions. I just don't want to make assumptions about whatever.

Courtney Jones:

Federal poverty level. Some of them use that, some of them do not. I always encourage patients and loved ones to don't get discouraged. There's always a way to try to have a conversation and see if you can qualify for an exception. We have been successful in appealing exceptions to some of these eligibility criteria based on the medical cost of care. And showing them even though that they are a little bit above what that financial eligibility is, their current cost of care far reduces their expendable income. And that has led to some approvals based on that. So I always encourage to either have that conversation and make those appeals or reach out to a case manager or navigator to assist.

Melissa Rosen:

Okay. Thank you. Somebody asked specifically about a test that was being denied. That's the breast cancer index test because it was considered out of network, but the test is proprietary. There are no other options for it in terms of ... there's no generic for the test or anything. And is there any, aside from the appeals you were talking about, and this person said they had already appealed that anything they can do, it's pretty important test

Courtney Jones:

If it's proprietary to that one network or one facility, besides the appeals process, and then having the conversation with that facility to see if they have any assistance programs available. Because it may happen often. Being that it's only that one. The only other thing that I can think of is we do what we call alternative assistance, meaning that we may not be able to solve that one issue, but we can try to find other avenues of financial support to offset the costs so is there another-

Melissa Rosen:

That is a really important thing you just said. I just want to make sure that people understood what you said, right? Can't lower the cost of that one test, but might be able to offer assistance with other things so that they could then afford that one test. I think that's very important.

Courtney Jones:

Yeah, our case managers utilize that skill often. Is there a financial assistance program that we can help get some insurance premiums covered for three or four months that will then reimburse them the cost of their insurance premium that they can then use that money to then pay for that test. So that would be my other suggestion is alternative assistance.

Melissa Rosen:

Okay. Thank you. That's a great tip. A couple of specific thoughts like people are asking, are there any grants for survivors wanting to start small businesses? Is there something specific to mortgage assistance for those facing cancer?

Courtney Jones:

I am not aware of financial assistance to establish any, you know, support programs or any organizations that I would have to defer out to have another conversation with a financial advisor or financial support institute. But the other question you mentioned, can you repeat that part again?

Melissa Rosen:

Mortgage, mortgage assistance.

Courtney Jones:

Okay. Yeah. There are some organizations. And again, we look locally and nationally that have some financial support. Mortgage is a little difficult I'll be honest. And again, that goes into offsetting costs or checking with your mortgage institution to find out if they have assistance programs available. Sometimes there's deferment.

Melissa Rosen:

Right.

Courtney Jones:

You have to ask some appropriate questions because they could defer a month and then you're hit next month with two payments. So you have to understand what that deferment means. But also some people have signed up for insurance through their mortgage company and are not aware that they have that disability insurance that they may be able to show what their medical disability is and then they can defer without any penalty, a couple months or you know?

Melissa Rosen:

Okay. Perfect. This one seems a little bit more general, and so we're going to ask Dr. Liang this. Somebody asked, why are these financial issues not often addressed ahead of treatment? And is it legal for hospitals to refuse to let you speak to a supervisor to work out a payment plan or can they refuse to treat you? It sounds like this person may have had a bad experience speaking to the wrong person.

Dr. Maggie Liang:

Yeah, I mean most of the time a provider office, or at least hospitals particularly do have to have a financial office that can then help with payment plans. Certain hospitals actually receive funding from the government that says that they have to have sort of the charitable programs or financial assistance program. So there should be someone. I do think, you know, I hear from, I've heard from patients in my research and things that sometimes it can be sort of opaque, even who that is or it's sort of hidden. So I think sometimes that can do the job [inaudible 01:07:46].

Melissa Rosen:

Are you allowed to negotiate with your doctor's financial person or the hospital's financial person? Can you try to negotiate or is that something that will be shut down immediately?

Dr. Maggie Liang:

I think usually they have guidelines in terms of payment plans. And then I think I was responding to a different question, but I do think some of the challenge, so I'll just say in California especially, but I also practice in Alabama. But there are just so many insurers and every insurer has so many little mini plans that have very specific networks of providers or hospitals. And a patient, when they sign up for insurance, they may or may not even have the illness yet to even know to say, is there this type of provider? So I think sometimes that's the challenge.

So I do think leveraging calling your insurance company, there are actually case managers usually that you can request to have a consistent person you talk to kind of figure out, okay, how do I figure out which doctors are my network? And if I want to see an out-of-network provider because I have a specific situation, how do I go about that because I do think without talking to someone there sometimes the health systems have challenges, so that's another avenue to find someone to help you.

Melissa Rosen:

I Appreciate that. All right, we have time for two more questions. Dr. Liang, we're going to stick with you for this one. You were showing us images on your slides of all of these apps to reduce financial burden or help people manage the situation. Are there any that are actually out there now that our participants and our callers could download to help them through this? Or are they all really in the trial version?

Dr. Maggie Liang:

Yeah, that's a good question. I should actually look for other ones. So those two I could just relook to while I was waiting. So it does seem like they are just for the research participants for now, but I assume if they find that it's helpful and then get some more feedback from people using it in their actual day to day lives, that then the goal would be to make it more broadly available. I do know just from loved ones that have gone through ... there are some, especially for the question about budgeting, obviously there are budgeting apps, but then there are healthcare budgeting apps.

I should look up some names. I don't know them off top of my head. And then I do know certain and PAF may, Patient Advocate Foundation may have this. I know other organizations that sometimes I've done talks like this with triage cancer have Excel sheets that are pre-templated. So then people who want Excel sheets can do that. At the end of day, some people feel more comfortable just having a binder and putting everything in the binder and having just a paper log of what's going on. So yeah, so those are some maybe tools that are immediately available.

Melissa Rosen:

Okay. Thank you for that. Okay, last word, Courtney. I know that you've addressed this in many different ways over the course of the last hour, but we have gotten so many questions about what's available, what resources are available for individuals that really are above the FPL but are still really struggling now. Instead of going through it all, can you just say one or two first things that somebody who finds themselves in their situation should investigate or connect with?

Courtney Jones:

That's a very good question. There's a lot of different things that come into play, even aside from the FPL. So I would always encourage to reach out and have a case manager speak and look at the whole situation and not just focus so much on what that income is. But there are a lot of the resource tools, like I had mentioned, our resource directory. I know Dr. Liang had a list of resources on one of her slides that have a lot of financial support available through them,

Melissa Rosen:

As is the Sharsheret website.

Courtney Jones:

Yes, yes. But every organization is so varied in what eligibility criteria is, but being over income, I would encourage to look at what is your area of support or what is your area of need? Is it medically related or truthfully, cost of living needs? And then that will kind of lead you down different paths because there are ways to appeal and like I said, make negotiations or discussions for medical cost of care as we were mentioning the charity assistance programs at hospitals, making the appeal of, yeah, you may be over the FPL. However, this is what the total care is going to cost. And there may be some reduction. It may not be a 100% of care reduction, but it could be a 30% or 40% based on the different levels of where you are income wise.

And then with the cost of living, that's a lot of different organizations and whatever their eligibility criteria is. But also having these honest conversations with your utility company to make payment arrangements, mortgage companies to make payment arrangements, things that can help you also reduce late payments, interest penalties, those things that also come on top of that, that can help try to make it a little bit more manageable.

Melissa Rosen:

Thank you. I actually think that's great advice. Even to kind of segregate the expenses you have because that will guide where somebody should look first. Okay. I wish we had more time. I'm grateful for the extra time both of you gave and all of you who are here today gave. A Lot of great information, a lot of places to get resources. Please let us know if you would, the evaluation actually gives you an opportunity to connect for some financial guidance or resources and guidance, where to go, so that remember to take up. Thank you for putting that back up. I want to thank everybody again and wish everybody a great night. Thank you.

About Sharsheret

Sharsheret, Hebrew for “chain”, is an international non-profit organization, that improves the lives of Jewish women and families living with, or at increased genetic risk for, breast or ovarian cancer through personalized support and saves lives through educational outreach.

With regional offices in the Midwest, Northeast, Southeast, West, and Israel, Sharsheret serves 275,000 women, families, health care professionals, community leaders, and students.

Sharsheret creates a safe community for women facing breast cancer and ovarian cancer and their families at every stage of life and at every stage of cancer - from before diagnosis, during treatment and into the survivorship years. While our expertise is focused on young women and Jewish families, approximately 25% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

As a premier organization for psychosocial support, Sharsheret's Executive Director sits on the Federal Advisory Committee on Breast Cancer in Young Women, Sharsheret works closely with

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the Centers for Disease Control and Prevention (CDC) and participates in psychosocial research studies and evaluations with major cancer centers, including Georgetown University Lombardi Comprehensive Cancer Center. Sharsheret is accredited by the Better Business Bureau and has earned a 4-star rating from Charity Navigator for four consecutive years.

Sharsheret offers the following national programs:

The Link Program

- Peer Support Network, connecting women newly diagnosed or at high risk of developing breast cancer one-on-one with others who share similar diagnoses and experiences
- Embrace™, supporting women living with advanced breast cancer
- Genetics for Life®, addressing hereditary breast and ovarian cancer
- Thriving Again®, providing individualized support, education, and survivorship plans for young breast cancer survivors
- Busy Box®, for young parents facing breast cancer
- Best Face Forward®, addressing the cosmetic side effects of treatment
- Family Focus®, providing resources and support for caregivers and family members
- Ovarian Cancer Program, tailored resources and support for young Jewish women and families facing ovarian cancer
- Sharsheret Supports™, developing local support groups and programs

Education and Outreach Programs

- Health Care Symposia, on issues unique to younger women facing breast cancer
- Sharsheret on Campus, outreach and education to students on campus
- Sharsheret Educational Resource Booklet Series, culturally relevant publications for Jewish women and their families and healthcare Professionals

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