Cancer and Self-Advocacy 101: What to Know in the Doctor's Office, with Insurers and at Work

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Melissa Rosen:

Thank you so much for being here and being with us this evening. We're excited to have you. Welcome. My name is Melissa Rosen. I'm the Director of Training and Education at Sharsheret. This evening's topic, “Cancer and Self-Advocacy 1 0 1: What to Know in the Doctor's Office, with the Insurers and at Work” is an important one that doesn't get the attention it deserves, and we're going to change that tonight.

Many of us in the cancer world, whether we're facing cancer or supporting someone with a diagnosis, speak about the team, the group of people who help us get through the experience. We instantly think of our oncologists, our surgeons, maybe even if we're lucky, a patient navigator or social worker. When we're reminded we include our spouse or partner, a best friend, maybe an adult child, and others who are there for us. Rarely, rarely do we remember to include ourselves as part of our team, but our voice matters and tonight we're going to explore what self-advocacy looks like and why it is so important.

Before we begin, I want to take a moment to thank Daiichi Sankyo for their sponsorship of tonight's program and the Patient Advocate Foundation and Triage Cancer for partnering with us on tonight's important topic. Before we get started, a few housekeeping items. Today's webinar is being recorded and will be posted on Sharsheret's website alongside a transcript of course, participants' faces and names will not be on that recording. If you would like to remain private, you have the option to turn off your video and rename yourself or you can call into the webinar. Instructions are in the chat box now for both options. Additionally, we now have closed captioning available to display live captions on the bottom bar, click captions and then show captions. You may have noticed you were muted upon entering the zoom. Please stay muted during this call. I'm excited to say we've received a great number of questions during the registration process.

If you have any questions that arise during the presentation, please type them into the chat box and we will be monitoring the box for them and present them during the expanded Q&A at the end of today's session. We are having that expanded Q&A and we will do our best to answer as many of the questions that have come in as possible. Just to note, we may be combining questions, so listen for the topic you asked about and not the exact wording you used when you asked that question. Also, a reminder that we cannot answer questions about specific medical or legal situations during this evening's program, but our partnering organizations may be able to provide one-on-one assistance. I want to remind you that Sharsheret is a national not-for-profit cancer support and education organization and does not provide any medical or legal advice. The information provided by Sharsheret and tonight's speakers is not a substitute for medical or legal advice, and you should not use this information as such, and of course always seek the advice of a qualified professional. Before we welcome our guest speaker to the screen, we are happy to have Heather with us. Now. Heather is a Sharsheret caller who will share how she advocated for herself and how that impacted her personal experience with cancer. Heather, welcome to the screen.

Heather:

Hi. Thank you so much for having me.

Melissa Rosen:

Sorry.

Heather:

Thank you. I'm sorry if it's a little bright.

Melissa Rosen: Nope. Perfect.

Heather:

I am so thankful that I get to talk to you guys this evening. It was, I am beyond being a breast cancer survivor. I had, I am below the knee amputee, so about three years prior to breast cancer, I had learned how important it was to advocate for myself and I had that experience, so when it came to breast cancer, this journey, I really had an opportunity to hone in skills that I'd already learned through my amputation journey. One of the main things I would recommend to anyone beginning this part is researching grants and speaking with your Sharsheret advocate that connects with you, that there's so much out there and for your children, for your spouse, for your caregiver, for you as the patient. There's help for bills, there's help for your children's events, there's gifts and opportunities for your caregivers.

That was an immense help to me throughout my entire journey and afforded me the ability to seek natural medications and other alternatives and through being able to afford seeking alternative medication, not just I did do chemo, I went through radiation, but I was also connected with a naturopath and learned that there was options for me because I am an amputee and osteoporosis is a huge concern that because I was progesterone estrogen positive and not HER2 negative, that I was able to have an oophorectomy and that was an alternative to doing the five to 10 years of tamoxifen and doing the oophorectomy instead of doing the drugs allowed me to have a completely different recovery. I know a lot of my friends that are in my breast cancer support group really have different outcome than I do with me leaving my uterus and having the ovaries and fallopian tubes removed, which has allowed me to not have the long-term side effects of tamoxifen or the different other prescribed drugs, which without having questions and seeking an outside opinion and a natural opinion, that option was never even presented to me, and I'm so thankful that because of the grants, I was able to seek a natural route and then because of a natural route, learn of other options that were a better fit for me, for my overall health.

Now, some people don't have the same health concerns that I do, and you know what? Those medications and your doctor's recommendations are perfect, but without me presenting and asking more questions in that doctor's office, I would never have learned about having an oophorectomy and I would be dealing with the breakdown of osteoporosis at a much higher rate. Another way that I, because of my limb, I know about HSpot hyperbaric chamber therapy, which you cannot do during radiation, but after radiation for healing, I had 35 rounds and my scarring and the burning was extensive, that it's kind of an unknown request. It was unusual for my radiation oncologist, but because I had access to it, he did a lot of research for me that I was able to do that after my 35 rounds and within about two weeks I was completely healed from all radiation burns.

I have no scarring, and the axillary webbing syndrome is much less because of the HSPot therapy. All of those things, without having done research and having known and coming to my physician and advocating for myself, my outcome could be very different. My pain, my side effects and scarring would be a completely different scenario for me without doing research and then making sure that my voice was heard in my physician's office and asking them to do research, asking them to go farther on what is the just generic treatment and asking them to look at me as a whole person and all of my healthcare needs and not just my breast cancer needs, and it truly changed the outcome of my scarring and my long-term side effects.

Melissa Rosen:

Wow. Thank you so much for sharing your story. The message that I took there was not about specific treatments, but that you actually did some research. You asked your doctors about certain things, advocated for yourself, and because of that had additional options and that's amazing, so thank you very, very much for that. We were really glad to have you with us, Heather.

Okay, we are moving on to our guest speaker. We are so excited to be joined tonight by Rebecca Bloom, author of the forthcoming book, When Women Get Sick: An Empowering Approach to Getting the Support You Need, which comes out next week. Rebecca is a Yale College and NYU School of Law, educated patient and workplace advocate. A former workplace and benefits attorney, Rebecca's longest and proudest affiliation is with the Bay Area Cancer Connections where served as a patient advocate and healthcare insurance and workplace advisor for women fighting breast and ovarian cancer for over 26 years. Rebecca serves as a listener, a learner, a supporter, and advocate for the women she supports around the country. Her knowledge of the complex roles that employers and insurers and medical providers follow as well as the dynamics that exist between patients and those around them helps her to provide foundational guidance to the women she supports so that they can integrate all available information with comfort and confidence and really focus on recovery and wellness. Rebecca, we are so happy to have with us tonight. The screen is yours.

Rebecca Bloom:

Thank you so much. Thank you everybody. I am so thrilled to be here with wonderful Sharsheret and I'm going to bring up my presentation right now and get started immediately. I also just want to say I'm thrilled to be here with the Patient Advocate Foundation and with Triage Cancer, two of the most wonderfully compassionate and effective organizations in the country, so thank you so much and I'm so glad to be here.

Let's get started. This is very personal for me. My mother and my sister are both breast cancer survivors. I have had an over quarter century high risk journey myself. This really means so much to me. This is also very professional for me. I ended up in a niche legal career that turned into something that I could really use to help more women get the care they need, get access to the care they need, get the coverage that they need, and access the benefits that they have earned.

So I'm going to jump right in and talk about what kind of help women should be asking for, and this is something, first of all, I just want to say my daughter is very talented and she made me these beautiful graphics. I love them, so thank you to her. So what I want to talk about here is setting yourself up for support. What does that look like? Well, it looks a lot like what we do in our day-to-day lives. We do it for organizations we work with, whether they're nonprofits or corporations or whether we're doing volunteer stuff in our kids' schools or anything else. We project manage, and when you have an illness, it's a project and if you set yourself up and draft yourself a great team, you're on the road to a better health journey, and that starts with a chief of staff.

So let's talk about what that looks like. Well, could be a doctor, could be a lawyer, could be a project manager or a nurse or a human resources professional, somebody who's competent, organized, and calm. We all have people like this in our lives and they love to do what they're great at doing. So it's about asking for that help, and that's really a big step in self-advocacy. Also, I don't only mean individuals, I mean organizations. They can also be part of your team, so SHarsheret, The Patient Advocate Foundation, Triage Cancer, local disease specific organizations like Bay Area Cancer Connections where I've been honored to serve for over 26 years. These are great team members. One of the tips I've been giving a lot, and I didn't realize it was revelatory because it's simple, but a lot of people have told me they never thought about it, is to connect in advance with a letter or an email or a call saying, hello, this is who I am.

I'm embarking on this journey. Would it be all right if I reached out to you with questions? Who would you send that to? You could send it to any number of stakeholders in the health space, in the workplace, in the insurance world, and then what have you got? You've got a thread in your inbox. You're not a stranger. There's somebody there who already knows you, so it's no longer an emergency and it's no longer a stranger. It's I'm dropping you a line and you know me, and that really works. On that topic, also, if there are waivers to be signed both inside and outside of HIPAA, those are things that can be done. Sometimes organizations will just say, this person, do you authorize this person to speak for you? It's not even a formal thing, but if you do that stuff in advance, your team can help you more efficiently.

Some other great team members, nurse navigators at hospitals or health systems, social workers, patient advocates, advisors at women's health organizations, disease specific or not, these are people who are trained to help people when they're on these journeys, disability and workplace experts. Disability is so hard to understand. If you don't do it every day, it's worth connecting with somebody who does it every day. Administrators assistants and doctor's offices, case managers at insurance companies. We'll talk a little bit more about those human resources, people, unemployment at your place of employment, a big deal inside your community. Neighbors for things like rides, childcare, help with food, doctor and nurse friends are so helpful on a health journey, whether they're your friends or your neighbors. You always seem to get that report about that scan at seven o'clock at night. That's always when it hits the portal. And then what do you do?

Usually you flip out and you might just be reading a word in a lay way, and if you talk to somebody who reads it every day in a professional way, they might really be able to calm you down. That happened to me once. I was doing a stress walk and my neighbor, the OB/GYN, was walking her dog and she saved me that night because I was doing a stress walk. As I said, of course, your team should be peers who have been through or are going through a similar journey. If you make your journey a community event, it will feel like one to you.

Okay, let's talk about talking with your doctors. I was really lucky to be able to interview some wonderful doctors for my book, and I learned some incredible things that I really want to share with you because I think this is something that people don't really talk about that much. We tend to pedestalize doctors and there's even a little bit of fear and nervousness around talking with them, so I want to share this stuff. There's that graphic again, okay? Let your doctors know as a top line level that you view your health as a partnership. This is a tone setter issue. Set that tone. We're partners. That's a really big deal. Everybody's a person in this story. They all have lives and things they're contending with, so that mutual respect and that 360 healthy communication can get you really far.

Okay, taking it down a notch. Be really efficient and precise in asking your questions and reporting your symptoms. Example, look at the difference between my stomach is bothering me and I have a burning sensation in my upper left quadrant of my stomach. Can you imagine how much more a doctor can do with choice B right there? Help them help you.

Okay, on that note, ask them directly what's the best way to communicate? You'd be surprised to hear that most of them don't love that portal either, and yeah, it takes 48 hours. Be realistic and mindful about that. If you do put a message in, you know why they don't have time to check it. It's like checking social media. They're working all day. They might tell you, please leave a message at my front desk. I come at the end of the day, I get my messages and I return my calls.

They might tell you, here's my cell phone. Please use it sparingly, but if you need it, use it. Because for them, they'd probably rather get on the phone with you really quickly and resolve what's going on than go through all this back and forth and back and forth. It's hard on them too. Another thing about communicating with doctors is if you have financial concerns, tell them upfront, whether it's copayments, price of medications, procedures, let them know it might affect their decisions. They might be sensitive to it if you tell them, and if not, they don't know and you can end up hitting a brick wall that nobody has to hit if you say it in advance. Okay, we talked about research. Heather, everything you said was so lovely and thank you so much for sharing it. It was so helpful. You're going to do research, so try to be a good partner, when you do that research. Pay attention to things like cost, whether the things are covered. Are there false positives? Are there risks that outweigh the benefits? Educate yourself. That said, be careful with the internet. The internet is speaking one to many. It's not really speaking to you, even if when you look something up you think that's me. It might not be exactly right. It might be that the statistics mislead you. It's really good to read it and think about it, but don't read it at bedtime. I think if you can avoid that, don't do that, but you're going to read it anyway, so I'm not going to tell you not to, but at least just take a deep breath and think about the fact that this was not written to you or for you. So just because you found it by using the right search terms doesn't mean that you're reading your fate in black and white on that screen.

Just think about that, okay? Ask your doctors about medical trials. There's so many medical trials out there. There may be something that could lower your cost or get you free treatments altogether in a safe and controlled environment, or there may be something on the horizon that has enough proof but not enough for FDA approval that might really help you. Speak to your doctor about it. Also, word to the wise, I wish it were true that all your doctors are together. Melissa, you mentioned your team. I wish they were all sitting around the water cooler having a conversation about your case. I don't think that happens that often. Sometimes it does in smaller settings maybe, but we've learned to rely on these electronic health records and think they're all reading everything. Everybody saw each other's notes, et cetera, et cetera. But the truth is, if you really want them to coordinate and if there's something that can't just be read and reacted to and it needs to be a discussion, set one up.

You've got your team, get your team to help you do that, facilitate that communication. Make it easy, like I said before, help them help you. Alright, now we're going to talk about the thing that probably gives people the biggest of headaches, and I do call it The Beast and that's health insurance, but I want to give as many actionable tips as quickly as I can and it's going to be fast and I apologize for how quickly I'm talking, but there's a lot to say and I'm also really excited to see the questions. And when you hear from Triage Cancer and Patient Advocate Foundation, they're going to have so much great information too. So I'm just going to go quickly. So first of all, always think about your coverage in terms of how can I maximize it? How can I get the most out of this coverage?

So how do you do that? Understand what your plan does and doesn't cover, choose in-network doctors. If you're going to do a second opinion, that's a place you could go out of network. You know why? Because it's one and done. It's not a long treatment process. It's not a course of medication. So that might be a place where you go, okay, maybe I am going to pay a little bit more, but I'm getting somebody's brain. That's what I'm getting for. That seems like it's worth it. Also, there are a lot of organizations. There's one in California called secondopinion.org where you can get a second opinion for free. Doctors will come on Zoom with you and give you one for free. Other ways to maximize coverage, pay attention to those copayments, those deductibles, those caps always check on specialists being covered. There's a new law called the No Surprises Act, which is great because it says, oh, if you go in and your, let's say anesthesiologist isn't covered, they can no longer done you with a bill that you didn't see coming since you didn't staff the case, but it's a new law and it's going to take time to really work perfectly well, So you should still ask.

If you don't understand an explanation of benefits, things like codes or words that they used or a bill that you think is going to eventually come, call your insurer, take it on immediately, be proactive. And again, maybe it's not you, maybe it's your chief of staff or whoever they say is going to be doing that. Ask for and read the summary plan description of your plan, that's a plain English version of what your plan is. I think we all know that this language is really arcane and hard to digest. My first job out of law school was writing summary upon descriptions. I thought it was really boring at the time, but I'm really glad I had that job because it taught me to distill this headache stuff into something that's understandable. If you are financially stressed, I talked about it in the context of communicating with a doctor, but I also want to say, and Heather, you made this point too, ask about things like payment plans, community resources, grants, disease specific emergency funds, premium assistance.

Don't put off care or go uninsured, ask about this stuff because as Heather said, there are a lot of things available that you might not think. Okay, now let's talk about buying your own policy. And let's also note that women with cancer had a really hard time buying their own policies before the ACA because of the preexisting condition rules, and that was a whole back flip that had to be done to get women covered in those circumstances, and it was hard, and it's better now. Even though things have receded, it's still better now. There are more people covered. Okay, so first of all, it's not like you're getting an estimate for offense. Don't settle on the most expensive and pick the one in the middle. It isn't really the price of the plan that matters. What matters is can you use the doctors and the healthcare systems that you are hoping to interact with frequently?

That's the thing back into it. Even ask them, do you like this plan? Do you like that plan? Because every year they drop some plan. So it'd be good to know which plan they prefer when you're about to buy one. So buy one that they like and that they take. That's important. Another thing is if there's a moderately priced clinic or an HMO that has amazing facilities and great personnel, you might find that's a smart choice depending on where you are in your journey. If you're already in active treatment, you don't need all the decision-making stuff, the diagnostics and the protocol setting and all that stuff. You need your treatment. In California, Kaiser Permanente is an HMO. It's way less expensive and they have beautiful facilities and fantastic doctors. A lot of women get great cancer treatment there. So sometimes that can be a great option depending on where you are.

Think about supplemental insurance to cover gaps or out-of-pocket costs if you're going to be traveling, if you know, have high co-payments. But be careful with those short-term health insurance plans. Usually they don't cover pre-existing conditions, so you think you're covering your bases or covering a gap by getting a short-term plan, but that's not necessarily true. By the same token, watch for any ads. Anything that you do on a Google search that comes up because it's not as regulated as it needs to be. So you could get caught in something that isn't really what you need that you pay money for. Go to healthcare.gov and let it run you right to your state marketplace. That's the best way to make sure that it's legitimate. Always ask your providers if they're in network and ask also about your meds. If you're on meds, find out for sure that they're in the plans formulary when you're buying it because it's important to make these calls because it's not always up to date online, but that's really important and that can cost you real money if you don't think it through.

So that's important to look at, learn the lingo, but also get help because there are assisters, there are navigators for free and they can help you look out for things like deadlines. Deadlines are really tough. This is such a big bureaucracy. If you miss a deadline, people don't want to hear why that happened.

That can be a hard thing. So you really want to watch for those. And you also want to look for financial assistance in your state marketplaces. Often, there is some.

Okay, now you've got your insurance. What else do you need to do to stay prepared? Well, actually a lot. So check with nurses, administrators, anybody that works at your doctor's office, ensure that, let's say they give you a drug, make sure your pharmacy stocks it because they just write the script and send it in. So imagine you going in and you're in the middle of an intense journey and you go there and then you find out, oh, we don't have it.

Oh, well, can you call another place? No, we can't. It's a controlled substance. Oh, what do I have to do? Oh, now you have to call the doctor again, get them to call again. This happened to me in real time once and it was super frustrating. So you still have to check stuff like that. Learn the names of the nurses and the staff. Pay attention to who answers messages in the portal. Why? That's the person who makes things happen in that office. That's why. And if you know these people's names and you have rapport with them, they can help you solve problems when they arise. If your coverage comes from your employer, have the name of the HR person who can help you get answers. They really have a better shot and better leverage with the plan than you do because they bought it, right? Goes without saying.

Ask for a case manager at your insurance provider. They're not going to give you one, but sometimes if you ask, you can get one and they can help you. And that helps because when you have to call and you don't have an extension, then you have to wait on hold forever. Imagine having an extension and a real person that you can reach out to. You might even get their email.

Okay, next, what do you do when you get a wrong bill or coverage that's denied? So I love this graphic. What does it look like to you? Alright, first of all, you ask for itemized paperwork and you ask from the provider and you ask from the insurance company, check the coding, check the plan names, check the numbers really carefully because so often they bill your old insurance policy, they do things, they make these silly mistakes that really you don't owe this money, but they send it out anyway. It happens all the time. It's a big machine and that's how it works.

Ask for help on all sides. We talked about all these people that are already on your team, right? Caseworkers, social workers, billing administrators, somebody at HR. All of these people can help you. Always pursue appeals processes because really, I hate to say it, but probably some percentage of the bills that get sent out that are wrong, it might be pretty clear that they're wrong and people pay 'em because they don't want to deal with the hassle. So I know it's hard, that's why you have a team. You drafted one, enlist help, make those appeals. You can win a lot of those appeals. Talk to your doctor about getting help with those appeals. They deal with it all the time. They can get them expedited. They can sometimes prescribe alternative medications if the one that you need isn't getting paid for.

Alright, I want to talk about the workplace. So there's a whole bunch of laws that apply and they're very complex and interlocking and really I think when you're not somebody who deals with laws all the time, you go right to is this a lawsuit? Is this a thing? What am I going to do here? Stay practical. Usually it's just more about knowing what your rights are. I've almost never seen any of these things escalate to that level. The first thing always is think about how to maintain your health insurance for as long as possible. You're thinking about pay and you're thinking about health insurance. Those are the two big things. But health insurance is the biggest thing when you're on a health journey. Llearn about leave options. There are paid leave options and unpaid leave options. Learn about all these things. Find out about disability benefits. There's state disability, and then there are also some private disability plans that different companies have.

Try to figure out what the landscape looks like for you. Are there early retirement options? Could you say maybe it's time for you guys to terminate me and there's a severance package available? Explore all your benefits, flexible spending life insurance cash out, some life insurance policies have a thing where you don't have to pay the premiums when you're on a health journey, but you still get to keep the coverage. There's all kinds of stuff that you have that you may not know that you have. So things like loans to yourself from your 401k or hardship distributions from your 401k. There are all these things in the workplace that can work for you. You just have to be paying attention to all those things, and I know it's complicated and that's the reason I tell you to get a team. Also, if you happen to be partnered, ask about your partner's benefits and also there are caregiver benefits, so these are all things that can be brought to bear.

Find out if your employer provides sick time. Find out what the policy states. I learned through working with a lot of women here in California that there's actually sick time banks in a lot of companies where people donate their sick time when they don't use it and people who need it take it. Imagine that. So it happens, right? Ask for access to your employee handbook online or hard copy. Nobody does hard copy anymore so that you can read about all your benefits because there's a wide array really. There's so much more than you think there is. There's more than health insurance.

Okay, the last thing I want to say is find out about peer support inside of your employer. There's so many wonderful peer support groups, especially at larger employers. Leadership groups, women's groups, and they have resources and support for you. No question about it. So that's where the segue goes to what I want to say next. No woman has to go this alone. That's my real email address. Please feel free, reach out to me, anybody can, anybody. That's my website. That's my Instagram because I don't have Facebook. So that's that. And I just am so excited for you guys to bring your questions and to share thoughts here tonight. So thank you so so much, Melissa and Deborah, and everybody, just thank you,

Melissa Rosen:

Rebecca, thank you so much. You have shared such practical information that we can all benefit from, and I know we're all grateful. Now I want to ask two special guests to join us for an extended Q&A. We're going to bring them up on the screen. Joanna Fazi Doran is a cancer rights attorney, author, speaker, and the CEO of Triage Cancer, a national nonprofit organization providing free education on practical and legal issues that may impact individuals coping with cancer and their caregivers through events, materials, and resources. Joanna has spent more than 30 years working on behalf of individuals with cancer. We also have with us Courtney Jones. She's the Senior Director of Case Management at the Patient Advocate Foundation where she leads the strategic direction daily operations of the case management department. She also advises the executive leadership on emerging healthcare trends, helping to shape the programs that advance PAF's mission to remove barriers to care for patients nationwide. And Courtney has been with PAF for more than 20 years, so we have more than 75 years of combined experience here. We can answer your questions. I do want to point out that both Patient Advocate Foundation and TriageCancer are longtime Sharsheret partners and we're grateful to have everybody here. So again, there's still time to get your questions in. If questions have arisen during today's presentation, please put them in the chat box.

Okay. I do have some questions that are geared towards specific people, but for most cases I'm going to let you guys duke it out as to who's the best, most appropriate to answer each question. So why don't we start with an advocacy adjacent question to sort of set the tone. So somebody asks, how do I know if my doctor is right for me? How do I know it's a good match? And this is really more, it's definitely advocacy. You need to learn how to figure that out, but not the legal stuff. So how do I know if I've chosen the right doctor? Anyone? Rebecca, I'm going to ask you.

Rebecca Bloom:

I’ll take it. So how if you chose the right doctor is, do you feel heard? Do you feel heard? It's a simple answer, but that's really what it comes down to. Doctors are under so many pressures behind the curtain that we don't see. They are managed from above. They are given, I don't know, eight minutes, 12 minutes, some crazy number of minutes that isn't enough to come and treat their patients. And for me, it’s do you feel heard? Do you feel like you have the time and the space to communicate with that doctor whether it's inside of that appointment or whether there are other ways to reach that doctor after hours, whatever the case, do you feel heard? That's the most important thing to me.

Melissa Rosen:

I think that's fantastic advice. Thank you very much. Okay, we're going to jump in with some very practical questions. Courtney. How should someone approach their employer about needing time off under FMLA and what documentation is typically required?

Courtney Jones of Patient Advocate Foundation:

Great question. Yes. I would always encourage patients to go and speak to their HR department and inquire about what you mentioned. Family Medical Leave Act - FMLA is often also how it is referenced and inquire as to there's typically a form that needs to be completed and then medical documentation that will need to be supplied from your medical team to explain and extend why you're asking for this leave. There's two different types of leaves that you can be looking for. It's FMLA, and then if your job or employer also offers short-term disability, so you would be best to inquire with both. Not every job offers short-term disability. Sometimes it's a benefit that's offered through your employer and sometimes it's a purchase benefit that you elect during your election time of choosing coverage and options. But it's important to seek both avenues and you can get them concurrently. So FMLA does not always require payment, so it just can pay up to a 12 weeks of leave, whether that's consecutive leave or intermittent leave. So if you're having times to have to take doctor visits, you don't need to take a whole week off or two weeks for treatment. You could just also ask for intermittent leave and only need to take the day for the appointment or a couple hours for an appointment. But it's a total of 12 weeks if…. you don't still has to offer that time to you.

Melissa Rosen:

Courtney, I think we're losing you. Somebody did ask right now if FMLA is unpaid. Can you clarify that?

Courtney Jones:

Yes. Can you hear me now?

Melissa Rosen:

Yes.

Courtney Jones:

Okay. Yes, it can be unpaid. If you do not have a leave on the books like vacation or sick leave, it can be unpaid. That's why I always say to speak to your employer about short-term disability options because then you will be taking FMLA leave while being paid under your short-term disability policy.

Melissa Rosen:

Okay

Courtney:

But, Yes, FMLA can be unpaid.

Melissa Rosen:

Okay, great. Let's move on. Thank you. I see some questions are coming in, so I'm just trying to stay on top of those as well. You know what, Joanna? Can you just frame what questions should we be asking to our healthcare team to make sure we have access to the care we need?

Joanna Doran of Triage Cancer:

I think that when we are going to the doctor and we're seeking care and they prescribe us care, we do need to ask a couple of key questions. And Rebecca introduced the importance of this idea that we really need to communicate and not just assume things are going to go smoothly, but to proactively have these conversations, the first question is to find out, do you need a pre-authorization for care? Do you need to get permission from your insurance company first before you get that care? Because if you don't get that permission, then the insurance company cannot cover it. They can say, we're not covering any of the care you just received. So proactively asking your healthcare team, do I need pre-authorization for this care and are you going to help me do it? Lots of providers do this for patients on the backend, and patients never even know what's happening, but it's the patient's responsibility to make sure they get the pre-authorization.

It's not the providers. So that's why proactively having that conversation with providers is so important because you want to make sure if they're not going to do it, you have to do it. So once you get that pre-authorization, or maybe you don't get that pre-authorization and the insurance company denies it, so what do you do then? Is the provider going to appeal that denial of pre-authorization for you or are you going to have to do that yourself? So making sure that who's responsible for what ahead of time, it can really clear up some of the challenges that we see happen on the other end where patients have already gotten care, they didn't get a pre-authorization, they didn't know they had to, didn't know their provider, didn't do it for them, and then they're stuck with huge bills. That's why those tips ahead of time and proactively communicating can be so useful.

Melissa Rosen:

Amazing. Thank you for that. Rebecca, what are some employee benefits that women might be surprised to learn they have when they fall ill?

Rebecca Bloom:

So that's a great question and you know, everybody is most concerned rightfully about their health insurance coverage and they should be. But first of all, in today's world, there's all, there used to be this thing called the cafeteria plan a long time ago, I think. Do they still have that, Joanna? Do you know?

Joanna Doran: They still do have it.

Rebecca Bloom: It was like section 125 of the tax code, I think it was, right? Yeah. There's a menu of benefits and there's all these newfangled companies that are trying to take over and help employers administer them and have more choice and more flexibility. But there's everything from, there's the financial thing where you can take loans from yourself, from your 401k plan, let's say. There's that, but then there's the social emotional stuff. There's meditation, there's gym membership, there's different kinds of outside of the regular medical system treatments that employers are beginning to think about giving employees money to pay for.

So yeah, there are so many things under the umbrella of employee benefits outside of your traditional health stuff. And if you think about it, we can't allow a third party payer system to govern all the things that a woman needs when she gets sick. If we do that, what are we going to end up with? We certainly can't do that. So we have to think there are these other things that, yeah, I mean maybe they still need to be evidenced based, there are still other criteria that an employer might have, let's say, to offer these benefits, but it's got to be outside of health insurance. So there are so many. I hope that answered the question okay.

Melissa Rosen:

Yeah, no, that's great. Okay. How can someone get insurance to protect themselves if they need to unexpectedly stop working in the future? And is that even possible once a diagnosis has occurred?

Courtney Jones:

Yes, that's a great question. I can speak, and you had mentioned this, Rebecca, in your great presentation about the Affordable Care Act and what that's done for insurance coverage and not having pre-existing conditions. So there are several options if you are employed upon gaining and continuing your medical insurance, you have the option of COBRA. So that is to extend your current employer plan, but you'd be paying all premiums. Now those can be a little pricey, but you would still maintain the exact same coverage that you had with your employer just from a COBRA benefit. That takes typically on average if you're leaving 18 months to be able to maintain, as long as you're paying those premiums, again, they are very high and pricey. So then you also can go under the marketplace, which Rebecca was talking about in her presentation, and look for plans in different policies that are available through each state has their own marketplace options, and also applying for subsidies, which will help depending upon income, reduce those premiums and out-of-pocket costs.

Again, it's also important to make sure you're maintaining the network of patient, I mean, of coverage that you have so that you can still maintain your current care.

Melissa Rosen:

Perfect, thank you. So we have a couple of similar questions of situations where people have permission to be working from home because of their situation, but there's some in-person event that's coming up that they're concerned about, or someone who works at a school and they're immunocompromised because of chemo and worried about flu season. What rights do people have in situations like that?

Joanna Doran:

I'm happy to take that one, or at least start us off. So the Americans with Disabilities Act or the ADA is a federal fair employment law that protects people against discrimination at work and gives them access to something called reasonable accommodations. And reasonable accommodations are any change at work that are going to help someone either continue to do their job or return to work or even take time off work could be a potential reasonable accommodation. The challenge with reasonable accommodations is that they have to be reasonable based on your job responsibilities. So if you are a school bus driver, you likely are not going to be able to telecommute your job. So the types of accommodations have to relate back to your job responsibilities and also have to be useful in addressing the challenges that you're experiencing at work because of your medical condition.

So if you're experiencing a situation where you’re immunocompromised is telecommuting an appropriate reasonable accommodation, so you're protecting your immune system because it's compromised, so they have to be connected as well, and accommodations have to be effective for use specifically. So we don't kind of just generally make blanket statements about things, it has to be specific to you. So if somebody's in a situation where they are immunocompromised and they have the type of job where it's reasonable to telecommute or they have been telecommuting or working from home, then it could potentially be reasonable that they don't participate in an in-person meeting. But the details matter based on what that meeting is about and is it how important it is for someone to be physically present versus is it the type of meeting where somebody could zoom in to that particular meeting. So all those details are going to determine whether or not it's reasonable in that specific situation.

Melissa Rosen: Thank you.

Joanna Doran:

And then it's not just federal law. I'll mention there are also state fair employment laws in every state except Alabama and Arkansas that provide very similar protections to the ADA and give people access to those same protections. But state law is often better than federal law, and so they might even be more helpful to people than the federal law.

Melissa Rosen:

Interesting. Okay, thank you. We have time for a few more questions. So as unfair as this is, I'm going to ask you all to answer quickly. So we haven't really talked about managing insurance denials. I know all of you could answer that. Rebecca, I'm going to ask you to start, but if anybody has something to add to it, we can go from there.

Rebecca Bloom:

Yeah, I will just start and then I really hope that these guys jump in because really two of my favorite organizations, so effective and so wonderful and just go to in every way. So yeah, I would say there's a book that I read when I was preparing to write my book called Never Pay the First Bill, and it's written by a journalist and his point is well taken that bills get sent out almost like willy-nilly sometimes it feels like and you can expect them to be wrong. I mean, they're wrong enough of the time that you can have the expectation that they're wrong, which doesn't really help when you open a scary bill when you're already dealing with a health crisis. I mean, as much as I say that to you, it just doesn't. So I would say I really do think that people have to try to stay zen and recognize that this system is really flawed and that there are things that happen. I saw when I was advocating there was this, people kept getting bills that were about $800 systematically, and when I really looked at it, I saw they were all wrong, all the bills were wrong. And so I thought to myself, is somebody optimizing for the fact that there's this number where if it's under that number, you're just going to pay it because you don't want a headache, I have to say, I know, Joanna, you're laughing. That's why I think you should go next. Go.

Joanna Doran:

I will say, I think most people assume bills are going to be correct if they get a bill or if they get an explanation of benefits from insurance that it's right. And I think that we shouldn't start from that assumption. We should start from the assumption that it's not right and double check everything and ask questions of providers and ask questions of insurance companies to make sure you're not paying for things that you don't have to pay for. The internal and external appeals process for private insurance, those are some of the best kept secrets of our healthcare system. And there is limited data because insurance companies are only required in very limited circumstances to share this data. But we know for marketplace plans in one year, 48 million claims get denied, and 99.9% of people don't appeal them. So that's only 0.1% of people who are saying, I'm not going to take no for an answer and I'm going to make sure that I can get access to the care that I need that was prescribed to me by my healthcare team, presumably for a reason. So people who aren't making use of the appeals process are either going without the care that they need or they're trying to figure out how to pay for it out of pocket. And so if you can't tell, appeals are a bit of a soapbox issue for me, and I will just mention that we are doing a webinar at Triage in August on the appeals process that covers all different types of insurance because the process is different depending on the type of insurance that you have.

Melissa Rosen:

Joanna, if you could share that information, we will get that information out in the follow-up email. Absolutely. Okay. Listen, a lot of questions have come in, we've time for one more. I want to end on a different note, but I will say that some of these questions have been asked in different ways, multiple times, the questions that keep repeating. I'm going to ask the three of our question answerers now, if they could write short things about it and we will include that information in a follow-up. So we've asked about a lot of specific things, but one of the things that Rebecca mentioned is that, and she used a word, I can't even remember what it was now, but a word I had never heard of before where we pedestalize, is that the word you used? Doctors, right? It's a great word. We tend to be a little nervous around the grateful for the care they're giving us, afraid of offending them, things like that. And that may hold us back. A question I want to end with is how you advise women who are fearful as being branded as either hysterical or difficult and then worried about the type of care they're going to get if they've been branded in that way. Rebecca?

Rebecca Bloom:

Okay. So this is a great question and there's a wonderful book by Dr. Elizabeth Comen that I hope everybody gets to read that talks about this exact issue. So female hysteria is not brand new, and it's not something that is just endemic to the US healthcare system, although I think that we have some perfect storm conditions that tend to make it worse. So I would say when I think about what you want to do to avoid this problem is, as I said, you draft your team, you go in with your questions and you think carefully about what questions you're asking. Don't ask a doctor about billing. They don't know. Ask the doctor about the medical care and the protocol and the choices. Ask the right people the right questions, do your homework and plan ahead. Be an excellent partner, be an undeniable partner, but then ask every question and don't censor yourself.

Melissa Rosen:

Okay. And have the confidence to know you have the rights to ask those questions. Amazing, amazing. Like I said, there are more questions. We're going to try and get you all more answers, and as we begin to wrap up, I want to thank Heather for sharing her story. Thank you to Rebecca for providing important information and some inspiration. And thank you to Courtney and Joanna for sharing your very specific and necessary expertise. We are so grateful to have had all of you this evening. Thank you to our sponsor, Daiichi Sankyo, and to our partners tonight, Patient Advocate Foundation and Triage Cancer. I want to make you aware of an amazing educational booklet we have. It's one of our newer pieces and a fantastic resource. It's called Communicating with Your Healthcare Team. It's available as a download with the link just put in the chat box now and as a print piece.

And when you fill out the evaluation for tonight, there's an option to order a hard copy, so an added reason to fill out that evaluation. Please take a moment to do so, and that link is in the chat box right now. Additionally, Rebecca has generously offered two autographed copies of her book, and we will randomly choose two recipients from those who have filled out that evaluation. So another reason to click that link and fill it out. We have several exciting programs planned in the coming weeks. You can check out our full calendar by clicking the link in the chat or just going to our website. We realize there are a lot of links there right now. Please remember that Sharsheret is here for you and your loved ones. We provide emotional support, mental health counseling, and other programs designed to help you navigate through the cancer experience.

All are free and completely confidential, our contact information is in the chat box. I want to remind you that in addition to the additional information about your questions that we'll be getting you both Patient Advocate Foundation and Triage Cancer as well as Rebecca who shared her email address are available to help with many of these issues and Sharsheret has additional resources, please reach out as we come to a close. We want to put the evaluation link. Somebody asked if we can get Heather's information. I will reach out to Heather and see if she's willing to share that. And if so, put that in the follow-up information, the follow-up email. But the survey to the link, excuse me, to the survey is in the chat box one more time right now. We want to thank you for joining us. Once again, thank you to everyone and I hope you have a wonderful evening. Goodnight.