

Supporting the Supporters: Navigating Rights and Resources for Caregivers

National Webinar Transcript

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Presented by:



Melissa Rosen:

Welcome to everyone. Thank you for joining us this evening. My name is Melissa Rosen. I'm Sharsheret's Director of Training and Education. We're here tonight to discuss a topic that often gets overlooked. Those of us here understand that a cancer diagnosis does not just impact the patient, it impacts spouses and partners, parents and children, best friends, and so many others. While, of course, the focus is on the person who's been given a diagnosis, caregivers also need support. They need support to help process their own emotions surrounding the diagnosis of a loved one, and they need support in having their own needs met. That's what we're going to explore tonight.

Tonight's webinar is being recorded and will be posted alongside a transcript on the Sharsheret website. Of course, faces and names of anybody, but the speaker will not be on the recording. Still, if you'd like to be anonymous, you have the opportunity to do that, and the instructions on how to do that are in the chatbox now. Additionally, we now have closed captions, and if that is helpful for anyone, the instructions on how to access those are going in the chatbox as well.

Okay. First, a few housekeeping items. I want to thank the sponsor for tonight's webinar, the Florence and Laurence Spungen Family Foundation. Their generosity allows us to continue to offer important caregiver support and educational webinars such as tonight's program.

We received some great questions through the registration process. But as questions arise during the presentation, please use the chatbox, and we will address them during the Q&A at the end of the webinar.

As a reminder, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for 25 years because cancer is so much more than simply a physical experience. In addition to our many programs to help women and their families navigate different aspects of a cancer experience, I want to highlight our free Spungen Family Foundation Family Focus program, which is designed specifically to meet the needs of caregivers. If you are interested in learning more about the Family Focus Kit or ordering one, please check out the link in the chatbox now. We'll also include that link in a follow-up email.

As I move into the webinar itself. I also want to remind you that Sharsheret is a national not-for-profit cancer support and education organization, and does not provide any medical advice. The information provided by Sharsheret is not a substitute for medical advice or treatment for specific medical conditions.

The information provided by tonight's speaker is not a substitute for any legal advice. Always seek the advice of a qualified healthcare or legal provider with any questions you might have regarding a medical condition or caregiver rights.

Before we ask tonight's expert to join us, I want to introduce you to Janice. Janice is a different type of expert. With a unique caregiver experience, she is going to share with us this evening. Janice, thank you so much for being with us tonight.

Janice Feiner:

You're so welcome, and thank you for asking me to speak. My name is Jan Feiner, and I am the wife of someone who I have known since I was 16 years old when he was first diagnosed with osteogenic sarcoma and lost a limb to the disease. Fast-forward two decades, and he was now a melanoma patient who then became a melanoma survivor. Most recently, he's been treated with treatment. Well, he has undergone treatment for bladder cancer and is currently still undergoing treatment for bladder cancer.

You would think that with all of that history, that we would've been more knowledgeable about the idea that there could be a genetic link to his malignancy. But it actually wasn't until our daughter, Dina, who is now 36, went to a new primary care physician who said, "You're an Ashkenazi Jewish woman. Would you want to consider doing genetic testing?" I would say Dina is my daughter who lives with a fair amount of medical anxiety, and she was like, "Sign me up. The more testing, the better."

So she did the blood work, and I'll never forget the phone call because she said, "Mom, you won't believe this. I'm BRCA-positive." It was actually a big surprise only because even though I say David had never really considered genetic testing, that's not totally true. A few years before, his sister had been diagnosed with an aggressive form of breast cancer.

At that time, we had David see our local geneticist. Judy, my sister-in-law, actually, who's doing quite well several years out now was BRCA-negative. So the geneticist that David saw chose not to test him for BRCA, but that said... So we went through thinking that we were home free in that regard. When Dina found out that she tested positive, obviously, we both went through testing. David was then tested. We found out he'd never been tested and was positive.

We have three other children. All of whom also tested positive for BRCA1, the familial mutation. I'm happy to say that two out of our three daughters have already done their risk-reducing surgeries, including bilateral mastectomy, reconstruction, and fallopian tube removal. My youngest daughter actually is only 29, and she's hoping that she can push the decision out a few years. My son is being more vigilant with his skin care checks and other things that men should be doing.

When I think of myself as being the caregiver, I probably, like many of you, never really thought about it being a true role. It's just what you do when you want to be there to support your children, and your spouse, and whoever else is close to you who is going through a situation like this, whether it hopefully being prophylactic surgery or whether it being the illness itself.

I have told my kids many times that we are the lucky family, that we found out about this before any of our kids were actually diagnosed with a malignancy. I realize how fortunate we are, and that is not always everyone's story, so. But I will say what was probably most helpful to me was information, and that was information that I received through Sharsheret, including Peggy and through JScreen, Melanie Hardy, the director there. Both of whom, I felt like, really, dovetailed into one another, and helped us get through this, and guided us, and were there to answer questions and also, just the follow-up.

I don't know if anyone has had this experience, but it feels very comforting to know that someone is really watching out for you as you get a little bit further out from the original diagnosis and surgery. Just a few months ago, Peggy called me and said, "You're on my list to call for the year," and we talked about a recent Sharsheret seminar that was hosted by a doctor from UCLA where they discussed PARP inhibitors as treatment for ovarian cancer. I just feel like the information that comes to us is so empowering. If that's one thing that I found helpful, it was, hopefully, something also that you all will find helpful so that you can feel like you are there to guide your children through this.

Can I speak to what it was like to be a caregiver for my daughters going through mastectomy? I will say it's no walk in the park. It's an uphill climb for several weeks. Fortunately, there's a huge online community of women who have gone through the surgery and who, I think, provide a lot of really helpful information. That was very helpful to my daughter and everything from what mastectomy pillow you should buy to the fact that you need certain kinds of bras, and clothing, and things that will help make it... and I think just being able to be there, and share that with her, and hear the information, because I think when you're the patient, it is very overwhelming at times. Sometimes the information just comes in too quickly, and there's too much, and you have

to know when to back off or turn off the computer. But I think that's probably what I would want to impart, so.

Melissa Rosen:

Thank you so much for sharing. I took away so many things. I mean, you've really expanded our definition of what caregiver is not just to someone who's dealing with a diagnosis, but someone who might be having prophylactic surgery or considering prophylactic surgery, that you were a source of information for your family, and kept making sure that they weren't overwhelmed, knew when to pull the information back and when to bring it in. Incredibly helpful.

I often think that sometimes the cancer experience is more difficult for the caregiver than for the patient in some ways, because the patient knows they're doing everything they can to deal with the diagnosis, and the caregiver is always looking for something more that they can do. So thank you for that. We're very grateful that you were able to share your story. Thank you very much.

Janice Feiner:

Absolutely, absolutely. I will say just in closing that I think when you are faced with the initial information about your children or your spouse, or being diagnosed with this genetic condition, that you have to cry your tears, and then you got to get up, and move on, and know that they're counting on you to be strong. Any way that you can find to be able to serve in that role, I think, is so important and not to deny yourself whatever help you might need because it's different for everybody, so.

Melissa Rosen:

Thank you.

Janice Feiner:

Mm-hmm.

Melissa Rosen:

With that, that's a perfect transition, because that's what we're going to talk about tonight, how caregivers can stand up and be strong getting the support that they need and those... Whether it's support for Sharsheret, helping with legal rights of caregivers through Triage Cancer or whatever it is, that's what we're addressing tonight.

So now I'm going to introduce tonight's expert speaker. Joanna Doran is a longtime friend of Sharsheret. She is a cancer rights attorney, author, speaker, CEO of Triage Cancer, a national nonprofit organization that provides free education on practical and legal issues that may impact individuals coping with cancer and their caregivers through events, materials, and resources. We partner with Triage Cancer often.

Joanna has spent more than 30 years working on behalf of individuals with cancers, including five as an adjunct professor of law at Loyola Law School teaching a seminar on cancer rights law, eight at John Wayne Cancer Institute's Psychosocial Care program and Positive Appearance Center. She's also taught a community advocacy clinic as an adjunct professor of law at Wayne State University Law School. She's co-authored the book *Cancer Rights Law* for the American Bar Association, the first and only book of its kind. The second edition of this book was just released this year.

Joanna, thank you so much for being with us today, and we are looking very much forward to hearing everything that you can share with us.

Joanna Fawzy Doran:

Thank you so much. Thank you for having me. It's really an honor to be here with all of you. Just going to pull up the slides, and hopefully, you can see them okay. But I was asked tonight to talk about rights and resources for caregivers, and I do just want to mention how you can find additional information about what I'm going to talk about tonight because I'm going to give you a good overview, but I want you to know, if you need to get more information, where to go.

When I tell people I'm a cancer rights attorney, people look at me funny and inevitably ask me, "Well, what's legal about cancer? Why do you need a cancer rights attorney?" The answer is, really, almost everything is actually rooted in the law. So whether or not there is funding for cancer research, whether or not the Food and Drug Administration approves that research as a treatment, whether or not insurance will actually pay for that treatment is a legal issue.

Whether or not you can take time off work and not lose your job either as a patient or as a caregiver, legal issue. We just don't think of a lot of those things as legal issues. We think about them as just part of navigating accessing healthcare, but there are laws that provide protections, and benefits, and programs that can help us.

Interestingly, in the cancer community, we talk a lot about the financial impact of a cancer diagnosis. A lot of those legal issues contribute to that financial impact. I think caregiving actually brings this up, because when I hear from doctors a lot, they focus on the cost of care, and I often have to remind them that even if cancer treatment were free, there could still be a potential financial hardship, because if a patient needs to take time off work and doesn't have income coming in or their caregiver also has to take time off work and doesn't have income coming in, that's going to cause a financial impact on that family. So we try to make sure that people keep that in mind when talking about the cost of care.

But I often say if all you needed was a law to solve a problem, you wouldn't need lawyers, and you wouldn't need law enforcement. Right? Just having the law by itself doesn't actually solve all the problems. So it is really important that people know the laws exist, and how to tap into those benefits and protections, and how to navigate through accessing those protections. That's really where triage cancer sits.

So we do that by providing free educational events across the country in person and online, but we also have, on our website, lots of resources and materials in different formats. So I want to point this out because we do have a resource page for caregivers specifically. So if you go to our Caregiver Resource page, you can find all the resources and information that is relevant to caregivers.

It also matters where you live. So where you live is going to give you access to different types of protections because of the law. So we have state-specific resources on our website, and we have charts of state laws that actually provide information about different areas of the law, including how to take time off work and some of those caregiver protections that are relevant to our conversation tonight.

So I want to tell you about the employment rights of caregivers and some of the limited ways that exist that provide income for caregivers. But I also want to just mention some of the other practical things that are relevant to think about and some of the resources that are available. I'm not going to talk about it tonight, but I don't want to forget to mention that caregivers often find themselves in a situation where they're helping the person they're caring for navigate health insurance, whether it's dealing with denials of coverage or figuring out if something is going to

be covered or those medical bills that come after care. So we do have a lot of resources to help people navigate those topics as well. So I just want to mention that.

So when we talk about employment rates, there's actually a lot of places to go for information about your employment protections. There are laws that we call fair employment laws, and these are laws that protect people against discrimination and also give them access to reasonable accommodations. I'll explain that more in just a minute. But these are laws that exist at the federal level, like the Americans with Disabilities Act, but they also exist at the state level. Sometimes those state laws are better than the federal laws or sometimes they're the only thing you have access to because you don't qualify for protection under the federal law. So that's why it's relevant to not just know what's available to you at the federal level, but also at the state and even local level.

There are also laws that we call leave laws, and these are laws that let us take time off of work for a variety of different reasons and provide job protection and sometimes even health insurance protection. Again, they exist at the federal level, like the Family Medical Leave Act or the FMLA, but they also exist at the state, the county, and even city levels as well.

Then, sometimes we work under an employment contract. That contract is going to give us more information about what benefits and protections we have access to at work. If we are a member of a union, that union bargaining agreement is also going to provide additional information about benefits and protections at work. But we often forget that the law just provides the bare minimum of what employers have to do.

There are so many employers that go above and beyond those minimum requirements. So that's why we always encourage people to look at their employer's specific policies. That could be things like insurance benefits, but it also speaks to how you can take time off of work. In most cities and states around the country, if you're taking a sick day, it's because an employer chose to offer that benefit, not because they were required to under the law. So it's good to keep that in mind, that if you have access to sick time or vacation time, that's not a requirement of the law. That's because an employer wanted to provide those benefits.

Employers can also have other types of policies, like can your coworkers donate their hours to you so you can be able to take that time off? Those are things that are going to be specific to your employer, and they're usually written in some version of an employee handbook or manual, or some type of policies and procedures document.

If you work for a smaller employer, they may not have all of those things written down. But generally speaking, there is somebody who can answer those questions. So if it's the owner of the company or if it's the office manager or the person you turn your timesheet into, somebody has some information about how your employer handles these types of situations.

So I want to talk a little bit about the Americans with Disabilities Act or the ADA, because most people are familiar with the ADA in the sense that there are accessible parking spots, there's accessible bathrooms, there's ramps into buildings, but there's an entire section of the ADA called Title I, which focuses on the employment of people with disabilities.

So the ADA's Title I only applies to private employers with 15 or more employees, or state or local government employees. Federal employees are also eligible for the protections I'm going to talk about, but they're available under a different law. They're available under the Rehabilitation Act of 1973. So that's a wonky nuance under the law, but the same types of protections are available.

So in addition to working for the right type of employer, you also actually have to be qualified for the job, and you have to have a disability under the ADA's definition of disability. Now, we talk about all sorts of laws and programs, and every single law and program has a different definition of disability.

You might be asking why am I talking about an individual with disability if I'm talking to caregivers tonight. The reason why is because the ADA does protect people who currently have a disability and who have a history of having a disability. It also protects people against discrimination. There is this line in the ADA that says people who... Well, maybe I'll say this one first. When an employer starts treating their employees differently because they have a medical condition, they're regarding that person as having a disability, and that's really the heart of discrimination, because it's not about what's going on with you and your medical condition, it's about your employer's perception of you.

So we call this the regarded as a prong in the ADA, but what I want to get to tonight... So all of that was to lay some foundation to this moment, which is that there is a line in the ADA that says people who associate with a person with a disability are protected against discrimination at work, and that applies to caregivers. So, caregivers, because they associate with a person with a disability, are protected against being treated differently at work because of their caregiving status.

Really, the bottom line of the ADA is that an employer can't take into consideration your disability or your status as a caregiver when making employment decisions. Unemployment decisions are things like hiring, firing, benefits, promotions, bonuses, pay structures, assignments. Any of those decisions cannot take into consideration someone's medical condition or their status as a caregiver.

I think that we often see examples of this in the cancer community where caregivers might be passed over for a promotion because the boss thinks, "Oh, they've got a lot on their plate right now, so we're not going to give them a promotion," or, "We're not going to give them that assignment because they have a lot on their plate," or, "Maybe we'll demote them because they can't be everywhere we need them to be."

So those are the types of things that employers are not supposed to do, and the ADA does provide a protection against or across all phases of the employment process, which means protections exist for job applicants as well as employees. So at every point in the employment process, people have access to these protections.

Now, I mentioned that this applies to individuals with disabilities and to caregivers when we're talking about protection against discrimination, but only individuals who currently have a disability or have a history of having a disability have access to the reasonable accommodations under the ADA. Reasonable accommodations are any change at work that can allow someone to continue to do their job or to go back to work. So when somebody has a medical condition that's affecting them, those reasonable accommodations can be very useful to help them and support them in that transition either while they're going through treatment or returning to work.

You can also see lots of value in caregivers having access to those accommodations, whether it's a change in work schedule or maybe being able to work from home or a different location so that it's easier to be there to support the person you're caring for. But unfortunately, under the ADA, caregivers are not entitled to accommodations. But that doesn't mean that you couldn't ask for one, because most of the time, employers want to keep good employees, and they really just want to be able to facilitate an employee being able to continue to do their jobs.

So if you approach the conversation with that perspective in mind that it's really inconvenient for employers to have to hire and train new employees, and so even just from a financial perspective, many employers will approach trying to accommodate employees than come up against a situation where they have to let employees go. So it's good perspective to keep in mind that even though caregivers are not entitled to accommodations, it's still something that you could ask for and especially if you approach it from, "I want to be able to continue to do my job effectively, but I need this support from you." I think that it makes it easier for an employer to say yes.

I mentioned that the ADA applies to private employers with 15 or more employees. There are also state fair employment laws that are very similar to the ADA. But in some states, they're actually better than the ADA, and they're better than the ADA in a couple of different ways. Some states have a broader definition of disability. Some states specifically list cancer as the type of disability to be protected under the law, but many of them actually cover smaller employers.

So this is a chart of all the state fair employment laws that actually cover smaller employers in their state. So if you're in Illinois, for example, it's one or more employees. So all employers in the state have to provide these protections. If you're in California, for example, it's five or more employees. So if you are in Illinois, and you are looking for these protections, and you work for an employer between 1 and 15 employees, you're actually not looking at the ADA for protection. You're looking at your state fair employment law for protection. So this is an example of why it's helpful to know what's available at the state level, not just at the federal level.

There are also similar types of local and state leave laws, and leave laws take lots of different formats. So it could be state versions of paid family leave. It could be just paid general leave that you can take for any reason. It could be unpaid leave to take family members to routine medical visits. So these laws are all over the place, but we do track them on our chart of state laws, and we have additional information on our State Resources pages.

But I really want to focus on the FMLA for a few minutes because this is the federal law that allows employees to take time off for their own serious medical condition or as a caregiver of a spouse, a parent, or a child. That is a very limited definition of family. It's just spouse, parent, or child. It's not parent-in-law, or grandparent, or sibling. It's just spouse, parent, or child.

In order to use the FMLA's protections, you have to work for a large enough employer. Here, we're talking about private employers with 50 or more employees or any local, state, or federal government employees, and you have to have worked there long enough, meaning, 12 months, and you have to have worked there 1,250 hours in the last 12 months you worked for the employer.

So that's a lot of hurdles to jump through to actually get access to these protections. But if you can meet these requirements, then you get access to 12 weeks of leave per year. So, every year, you get 12 weeks off work either for your own medical condition or as a caregiver, but it's unpaid leave, and most people can't take 12 weeks of unpaid leave and not have any income coming in. So many people who are eligible for the FMLA don't actually take it because they can't afford to, because they need that income coming in. But what the FMLA does provide that is really valuable is that it creates job protection.

We forget that if we're just taking a sick day or a vacation day, or even when we go out on disability benefits, all of those things are just about money. They're just about paying us for taking that time off work. Nothing about those things provides job protection. Really, when somebody is taking time off work, employers can hold that information against the employee, but the FMLA prevents that by putting people in relatively an effective bubble where you have access to job protection and you have access to health insurance protection.

So if you get your health insurance through work, and the employer normally pays 75% of the health insurance premium, and you pay 25%, that has to continue for the period of time you're on FMLA leave. Prior to the FMLA, employers would just tell people to go out on COBRA, and you would have to pay your full health insurance premium yourself. So the FMLA says whatever was the situation when you were employed continues while you're on leave.

The other benefit to the FMLA is that it's very flexible. So it can be used in segments of time. So maybe somebody takes off two or three weeks for surgery and recovery. Then, if somebody starts chemotherapy, for example, they could take one day off a week under the FMLA, or

maybe somebody is going to radiation appointments every day and is only taking off a few hours a day for those appointments. So it can be used in very small segments of time, but it can also be used intermittently. By that, I mean unexpectedly. So when somebody is not feeling well, they can take that time off of work.

We have been hearing more and more in the work that we're doing that employers are making employees use their vacation time and their sick time before they get access to the FMLA. That is actually not allowed, because it's the FMLA that provides job protection, and employers cannot prevent somebody from getting access to FMLA's job protection. So they can't delay that.

So if somebody is taking leave for a qualifying medical condition, they have to be able to have access to the FMLA. But that is different from when an employer says, "If you're taking FMLA time, we're going to substitute that unpaid leave with any accrued leave that you have." So if you have sick time, or vacation time, or just general PTO time, that's going to pay you for the period of time that you're out, but the FMLA is going to provide the job protection and the health insurance protection for that same period of time.

So they do work together, but to be totally clear, the FMLA is unpaid leave. So if somebody is getting paid during that time period, it's because they have accrued leave or because the employer has another policy that says they'll pay people while they're on FMLA leave or someone lives in a state that has access to paid leave. So there's a lot of caveats to that, which is why you have to understand all of these options to be able to figure out what you have access to specifically. We do have a lot of resources to help people navigate employment, and our Employment Resources page is broken down by where somebody's at in the employment continuum and also provides resources specific to caregivers.

The last thing I want to mention related to work is if somebody is taking time off work as a caregiver, how do you replace those lost wages? You don't have access to disability insurance because you don't have the medical condition, so what is there? There are very limited options. Unfortunately, we don't have paid federal leave.

We almost got it in the Inflation Reduction Act, and then it was pulled out at the last minute, so states have had to step in. So you can see the states that have created state paid leave programs. This year, we actually have a number of new states that will be providing these benefits where they had passed laws a few years ago and are just going into effect this coming year.

So these laws are all over the place as well. Some states, it's eight weeks of leave. Some states, it's 12 weeks. Some states, it's actually longer. So you can find this information on our chart of state laws on our state resources, and then we also have a quick guide to paid family leave programs as well.

If somebody is caring for somebody who has access to Medicaid and that individual needs help with activities of daily living, so things like getting dressed, or bathing, or housekeeping, or grocery shopping, they can actually apply for in-home support services through the State Medicaid program if that state offers it.

But what is interesting about this is that some states actually let family members get paid as the caregiver. So in some states, you have to hire a professional caregiver to do those things. But in other states, the family member can actually get paid. So it's often a way for family members to get paid for doing something they were going to do anyway, but at least they can bring some money in from the Medicaid program to provide those services. If somebody happens to be a veteran, there is also a program similar to that for individuals who are also veterans.

So I want to just say that caregiving takes lots of different forms. Caregivers also take lots of different forms. Caregivers might be family members, or friends, or neighbors, or coworkers. It

might be children, adult children of parents who are taking care of parents, might be grandparents taking care of grandchildren. Caregiving, really, is quite diverse in the United States, and there are lots of resources to help caregivers, but I think it's sometimes hard to sort through all the information to find resources that you can rely on, and so I wanted to share some of these as trusted, vetted resources for caregivers that provide lots of different support services.

I also want to mention that there's a couple specific to the cancer community, where if caregivers feel like they need support and need somebody else to talk to, Cancer Care is a great resource for talking to a social worker. Imerman Angels is an excellent resource if you want to be paired with a mentor. So they pair individuals who have cancer, but they also pair caregivers as well who are in similar experiences and can provide that sounding board and resource for you as well.

Then, there are organizations that also provide respite care. So if caregivers are in a situation where they need a break, maybe they're caring for young children and parents at the same time and need some help doing that, there are also resources that can help you find respite care in your own communities.

Then, there are lots of practical services that can be incredibly useful not only for the person you might be caring for, but also for you. So when you think about those daily tasks that take up time and energy, it can be like making dinner, or picking up kids from school, or running errands, or housework, or yardwork. I live in Chicago, so snow removal is a big thing.

There are all sorts of things that exist specifically to help with those types of needs where they create tools not only for patients, but for caregivers too to help support the person that they're caring for. It takes a little bit of some of the pressure off sometimes to know that you can tap your resources to get help in the caregiving that you're providing.

So there are resources to help plan meals for the week. There are calendar tools. People can create calendars like on CaringBridge of all the things that need to happen. So who can pick up the kids this week? Who can bring dinners by? Who can pack lunches? Who can take the kids to sports? There are all sorts of things that people can do. So often, we hear people want to support people in need, but they don't necessarily know how, and so some of these tools actually just create... They're good communication tools. They create opportunities to say, "This is what I need help with," both for patients and for caregivers, and you can just go and sign up to do those things.

So I just want to remind people that these exist. One that actually comes up in my neighborhood quite a bit are the local scouting troops. They do the snow removal, and they put it out into the community saying, "You can sign up if you need help with snow removal this season." Those are some things that people don't really talk about, but that can be so useful and helpful.

Then, for people who are caregiving remotely, which we definitely see a lot across the country, it might feel like people don't know how to actually be useful or helpful. I think COVID created a lot of opportunities and services that are useful in this circumstance. So if somebody needs help with shopping, maybe they could create an Amazon list and people can actually do that shopping so it gets delivered to their door, or same thing with meal delivery services or grocery deliveries, but also house cleaning. There's house cleaning services where you can make those appointments online, and people will show up to do those things. So these are not all cancer-specific, but it is helpful to just be reminded that there are tools out there that can be really useful for caregivers in this type of situation.

So as I mentioned on our resources topics page, we do have a page specifically for caregivers that talks about many of the services that exist in the cancer community and outside the cancer community and those protections and tools that can be helpful to caregivers.

The last thing that I just very briefly want to mention is if you're caring for somebody where you don't have a legal relationship to that person, and by that, I mean maybe you have a significant other, and you're not a spouse yet, or maybe you're caring for a friend. These are actually documents that might be helpful. If their best friend is their advocate when they're in the hospital and they want their healthcare team to be talking to their best friend about their care, they actually need a HIPAA form. The healthcare professional isn't going to talk to the friend without that HIPAA release form.

If somebody needs help navigating their insurance coverage or their financial situation, actually, having a financial power of attorney might be necessary for that person to actually be communicating with the insurance company on the person who they're caring for's behalf. Same thing with advanced healthcare directives.

So some of these things that are in the context of estate planning are actually really practical tools for caregivers to have while helping somebody navigate accessing healthcare. So we do have a state-specific estate planning toolkit. It provides general information about these types of documents and why you might want them or not want them, but it also has state-specific information about how you actually execute these documents specific to your state because it's different in every state.

Then, we actually pulled together the forms for every state where there are forms. Not everybody has access to state-specific forms because their state doesn't provide them, so they actually have to draft them themselves, but we have pulled all of that information together that does exist.

The other thing that I will mention. If people feel like that is overwhelming to think about and don't have the capacity to do all of that on their own, we do have a partnership with a platform called GoodTrust. It is an incredibly easy to navigate process if you want to create your key estate planning documents where it asks you questions about certain things, and then you go through and you answer the questions, and then it compiles all your documents.

It includes a will, and a trust, and advanced directive, and a financial power of attorney, but it also has things like pet directives, and then it has a storage vault where you can actually upload these documents and then give the key people access to those documents who need access. So it can be useful as a practical tool.

Then, I do want to mention that we provide a free legal and financial navigation program. So if anyone has questions about any of these things or other topics, you contact us at Triage, and we will talk to you for free, including connecting you with a financial planner. So if you are trying to manage your family's financial situation as a caregiver and need help doing that, we can connect you with a free financial planner as well.

So I want to just let you know that we also have lots of other ways you can get access to additional information, including our webinar series. We know that there's a lot of changes coming to our healthcare system next year, and so January's webinar will be on whatever we know at that point to be able to share with the community. Then, we also will be sharing any updates through our educational blog and our newsletter if that is a helpful resource for you to stay on top of things. So, with that, I will stop sharing and see if there are questions.

Melissa Rosen:

Okay. Thank you so much. You have a great way of clarifying what is an endlessly confusing topic for the vast majority of people. So thank you for that. I want to encourage anybody who has questions to put them in the chat now. A couple have come in, so let me just dive into what we have. one of the slides mentioned something about kinship laws. Can you talk a little bit more about what that is?

Joanna Fawzy Doran:

Yeah. So it's a group of laws, and again, it might be a little bit different in every state. But generally, what it does is it allows family members to use their own sick time to care for family members. That definition of who those family members are depends on how it's written into the state law, but it really came from the idea, really, for parents who need to take time off work to care for their children.

Melissa Rosen:

Okay. Another question that came in had to do with FMLA. It was just a request for clarification. So all those things you talked about, the time off that is not intermittent and all of those things, those are equally available for someone who is facing illness and for someone who's caring for someone facing illness as long as they are a parent, a spouse, or a child?

Joanna Fawzy Doran:

Correct.

Melissa Rosen:

Okay. Just to clarify. I see another question just came in.

Joanna Fawzy Doran:

But also, just to say that you might also be in a state that has a state family medical leave law that has a broader definition of family. So that's important to keep in mind, that someone might also have access to that law.

Melissa Rosen:

Which would be a wonderful thing. Yes. Okay. Somebody asked, "Do you have to be Medicaid eligible in New York State to qualify for the caregiver to be eligible for reimbursement?"

Joanna Fawzy Doran:

If you're talking about the in-home support services, which is that Medicaid program, yes, you do have to have Medicaid, and then apply for those services specifically for the caregiver to be paid for those caregiving activities.

Melissa Rosen:

The patient needs to have Medicaid for-

Joanna Fawzy Doran:

Yeah.

Melissa Rosen:

... for a caregiver to be... and Medicaid specifically, and not Medicare? Medicare is not-

Joanna Fawzy Doran:

Correct. Medicare does not provide those services-

Melissa Rosen:

Okay.

Joanna Fawzy Doran:

... or at least paid caregiving services in that way.

Melissa Rosen:

Okay. Is there anyone who is just not... I understand state to state, but just if we're going broadly, somebody asked, "Can you clarify who is not eligible for these caregiver legal rights?" Is there anybody just off the top of your head or it's just so nuanced state to state?

Joanna Fawzy Doran:

It is nuanced state to state. So take for example, if you live in... I'm trying to think of a state off the top of my head. If you live in maybe Texas, for example, your state fair employment law is not going to apply to smaller employers. So if you work for an employer with less than 15 employees, then you aren't eligible for those protections against discrimination at work. So you don't qualify for the FML... or for the ADA because it's too small of an employer, and there is no state fair employment law that covers smaller employers. There is a state fair employment law, but it's the same as the ADA.

Melissa Rosen:

Okay. So let me ask one final question because we're coming to the end. This might be a more complicated question. Somebody finds themselves unexpectedly caregiving for a spouse, a parent, a child, whoever it is. Let's assume someone who is covered more than not. Wherever they work, they're being given the run-around. They are being told they don't qualify, they're not eligible. Whether that's true or not, this caregiver, at the moment, doesn't have the interest or stomach for waging a legal battle. What is a person's next steps? What should they do?

Joanna Fawzy Doran:

I think we always say it's important to understand what your rights are and also, how to approach those conversations in a way that demonstrates that you know what your rights are, which in some cases might help conversations with employers if they realize you know what your rights are.

Sometimes, really, the run-around comes from ignorance. It comes from a supervisor or a manager who doesn't know what their legal responsibilities are under the law. So if somebody starts with their supervisor and their supervisor just says, "No, you can't take this time off," then it's about, "Well, who else at that place of employment can you speak to? Is there a boss of the supervisor? Is there an HR department or at least a person who is responsible for human resources activities? Is it the owner of the company?"

Generally, there's somebody else to have that conversation with, so it is a little bit about the nuance of understanding your rights and how to effectively get access to those rights. That's what I mean by needing to understand how to navigate the systems, because sometimes employees are in the position of educating their employers about what their employer should be doing under the law.

Melissa Rosen:

Okay.

Joanna Fawzy Doran:

It's unfortunate that that's the situation.

Melissa Rosen:

Yeah.

Joanna Fawzy Doran:

But if we can provide the tools and ammunition for employees to understand how to navigate the systems and the tools, how to have those conversations so that they are effective and that employees can get what they actually need, that's really the goal, because, frankly, we really don't want anyone to have to go file a lawsuit in the context of employment because that's not productive for helping someone get access to what they need right now.

That's going to the EEOC and filing a complaint. Then, they do an investigation, and then they give you a right to sue letter. Then, you have to find an attorney, and then the attorney is going to do more research. Then, they're going to file a lawsuit in court, and then it might be years before depositions, and hearings, and trials are done before there's a decision. So that is not an effective way to help people keep their jobs or be able to take time off work to get either access to the care that they need or to be a caregiver.

Melissa Rosen:

That's important to understand in the context of a conversation about the legalities of caregiver rights. Okay. That's great. I wish we had more time. There was a request to see the slides. Again, let me just let you know that when the recording comes out, the slides will be part of that recording, and you'll have access to that.

I want to thank you, Joanna, for sharing your expertise and your passion. I found, like I said, your presentation clarifying and empowering, and I hope all of you did too. Remember, you go to Sharsheret for that, that emotional support, the psychosocial needs, as well as all the other things we do. But if you have legal questions or employment questions, Triage Cancer offers that same kind of service we do for the psychosocial part. So, together, you have it all there.

I want to thank Jan too. Hearing from people who have been there makes such an impact, and you were so gracious to share your story with us tonight. Thank you again to tonight's sponsor, the Florence and Laurence Spungen Family Foundation.

As we near the end, I want to make you aware of just a couple of upcoming programs you might find of interest. A week from today, on Monday, the 24th, we are hosting our annual men's webinar entitled The Power to Prevent: A Men's Guide to Cancer Risk Reduction. This program is open to all regardless of gender, but I think it may be of special interest to caregivers because often, they neglect their own health as they support others. It's a good reminder that they need to address their health too. The link to register, it just popped up in the chatbox.

On Thursday, December 4th, we invite you to join us for demystifying clinical trials, what you need to know. The link for that is in the chatbox as well. Finally, one more link. As we conclude this evening, the evaluation link to tonight's program is in the chatbox. We ask you to just take... It'll take three minutes for you to share your thoughts on tonight's program. It's so important as we continue to plan programs to get a sense of what's been particularly helpful and what you would like to see additionally.

Remember that SharSheret social workers and genetic counselors are there for you to answer questions, to connect you to resources, to provide support, and you can reach our team through

the contact information in the chatbox. Thank you so much for joining us. Once again, thank you to Jan, and thank you to Joanna, and have a wonderful evening. Good night.

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 works closely with 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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