

The Art of Disclosure

National Webinar Transcript

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Presented by:



The Art of Disclosure

Elizabeth Saylor:

So I'm going to go ahead guys and introduce Melissa, and then Melissa, I'll let you get started. Obviously, the rules are very similar, as they are to our support groups, this is a safe space. Anything that anybody shares, we're going to keep confidential, and I think we'll probably have time for questions at the end.

Melissa Rosen:

Absolutely.

Elizabeth Saylor:

Some of you guys may have met Melissa before, when she came and shared with us, we've had a couple of times that we've had you in person, sometimes for other professionals and sometimes for patients and survivors and their families. So Melissa is the director of Sharsheret's Community Education. She has a master's degree in Jewish Communal Service from Brandeis.

Elizabeth Saylor:

She has been working in the nonprofit sector for over 30 years. Her professional experience includes in formal education and programming, advocacy and community outreach. Melissa's work has allowed her to facilitate unique and lasting connections among organizations in the diverse American Jewish community. Melissa oversees community education throughout the country for Sharsheret, training healthcare professionals, Jewish professionals, and Sharsheret's volunteers. She also manages the Sharsheret Supports partnership program. She is a breast cancer survivor, she's passionate about the Jewish community and cancer support and advocacy. And obviously Sharsheret is a wonderful organization, they're one of our partners in our funding through the CDC for some of our young women's programming.

Melissa Rosen:

Thank you very much for that wonderful introduction. I appreciate it. So, like Elizabeth said, my name is Melissa Rosen. Sharsheret is a Jewish organization that provides free emotional support to women and families facing breast or ovarian cancer. Although I want to be clear that our programs have absolutely no religious agenda, and in fact, a quarter of our callers have no connection to Judaism whatsoever. It is simply that if you are Jewish, there's some specific cultural and religious nuances, and we can help you with those as well.

Melissa Rosen:

And I'm happy to answer, after the presentation, any questions you have about programming at Sharsheret and how it might help you. Elizabeth mentioned I'm a breast cancer survivor, I am, I'm six years out from that. But I'm also a Hodgkin's disease or Hodgkin's lymphoma survivor, and I'm 20 some years out from that. And this presentation actually came out of a personal experience I had at the job prior to my joining Sharsheret staff. I was working in a nonprofit organization and loving my job and having a lot of impact, but one of my supervisors, she and I didn't get along. She and I didn't get along so well at all. When I was diagnosed, because of the type of job I did, I knew I had to step down because even an absence of six weeks would hurt the program.

Melissa Rosen:

And although most women obviously don't step down from their positions when they are diagnosed, I felt that I needed to do it. And that meant I had to tell this woman, who I had a perfectly fine professional relationship with, but not such a great personal relationship, that I had been diagnosed with breast cancer. Was not an easy conversation to have, I certainly didn't want to be sharing it with anybody quite yet, and I certainly didn't want one of the first people I shared it with, to be someone who wasn't one of my favorite people. And when I told her, her immediate reaction was to burst into tears, sobbing, and I wound up comforting her, someone who a week ago probably would've voted to have me leave the position because we didn't get along so well, and although her tears were real, they seemed very disingenuous to me, because I knew she didn't like me so much, and frankly, I was very resentful that I needed to comfort her in this situation.

Melissa Rosen:

So that interesting situation led to this presentation. And the reality is that cancer isn't something that we should be going through alone, it's so taxing. It's taxing physically, whether it's symptoms of the disease itself or side effects and reactions to the treatment. And it's taxing emotionally, we know that there's so much to process, there's so much that we have to work through. And so whether the assistance or the support we get is someone helping us physically by running errands or keeping us company, or just serving as a person to vent to, we shouldn't be going through this experience alone. And we should be able to accept support, and accepting support, necessitates sharing a diagnosis with some people.

Melissa Rosen:

Of course, there is that other side - where too much support is actually counterproductive, we can talk about that a little bit. But there are particular times when you may want to talk about your cancer, it may be when your diagnosis affects someone else's life, it may be that you're acting differently, and you'd like to explain what the change is from. You may need help with every day matters, you may need financial assistance, you might want to explain to someone that things have changed since your diagnosis. There are a lot of reasons that one would share a diagnosis. That being said, it is your decision. This is your story, and you are in control. Who to tell, when to tell, what to tell: you do not owe anybody an explanation. When we face cancer, there are a lot of things that are totally out of our control, this is not one of them. And this is a place that you can take control.

Melissa Rosen:

So, as you're deciding who to disclose the diagnosis to, choose those who you believe will support you and will make you feel safe. By the way, you don't have to tell everybody at the same time. It may be that you choose to tell people on a different schedule. Maybe family comes first, then friends, then colleagues, or a boss, others after that. Like I said, when you share is also your decision. Certain factors may impact that. It might be the effects of treatment, hair loss, weight loss, or you may need time off from work or modifications at work and all of those things, and so much more, may impact when you decide to share your diagnosis. But whenever you share, take some time to process your own emotions first, think about what you may need from others. Is it meals or rides? Is it a confidant? Someone to have fun with and forget what you're going through for a little bit, try and center yourself ahead of time. Now, all of that being said, I just want to point out that you can make the decision, to not share.

Melissa Rosen:

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There are a lot of reasons people choose to share and not share. And again, both are completely valid decisions that need to be respected by those around you. Depending on your situation in life, if you don't want to share, you could choose... I still don't want you to go without support, so you could talk to someone at Johns Hopkins, you could call Sharsheret to speak to one of our social workers and you could remain anonymous. You can call on a regular basis. If you opt not to share, that's fine, but please, please, please do not deprive yourself of much needed emotional support. Again, we talk about the ways to share. So when you share, and if you share, your decisions, but what you share is also your decision. Beyond the actual diagnosis, do you want to share a treatment plan, a prognosis, a change in disease status, such as a recurrence.

Melissa Rosen:

Once again, you can share a small part or you can share differently with different people. But sharing your diagnosis does not obligate you to share everything, and it doesn't obligate you to answer questions, often inappropriate, from people who don't need that information. So we've discussed your rights in sharing, as we've done that, we've briefly addressed some tips for actual sharing, but let's dig a little deeper. Decide who you're going to share with and in what order. Partner, children, close friends, boss, principals and teachers, colleagues, church or synagogue members, neighbors, and choose how. I recommend, if at all possible, a quiet, private space where you won't be interrupted. You can choose in person, by phone, in an email or text. For me, in person was better, but it's different for everyone. It might be that you might not be able to do it in-person because someone lives far away, a dear friend, or relative lives far away, or it may be that at this point, you're not emotionally able to do it in person, and this is the best way to do it.

Melissa Rosen:

Be clear about the amount of information you would like to share. And again, this may be different for each person. You may choose to share your emotions and your thoughts and feelings with those who are close to you and for others, just the facts are necessary. You could introduce the subject gradually, you don't have to feel like you need to just blurt it out. You can start with phrases such as, "I need to share some difficult news." Or, "I have some bad news, but there's a really good chance that everything will be fine after treatment." And don't worry about the silences. They can be filled by holding hands, hugging, asking someone what they're thinking about.

Melissa Rosen:

You can set the tone. If you are able to approach the conversation, feeling positive and hopeful, again, if you're able, that will reassure the person sharing the news. If you share some emotions, they may feel that they can do so as well. If you're just disclosing the facts, it may dissuade them from asking inappropriate or deeper questions. Before you share with anyone, it's helpful to know why you're disclosing and, what, if any, help you'll need. So for instance, if you're disclosing to a boss or colleague, you may want to ask about time off or modifications. With a spouse or partner, it may simply be a safe space to vent. With friends, you might be venting, you might be asking for help with meals or play dates, if you're raising a family, others, again, you're just informing and you need nothing from them. So, these disclosures, despite some of the inappropriate reactions you might get, are really about you, and you need to try and keep that in mind.

Melissa Rosen:

There is a special category where there's an exception and that is children. And honestly, it doesn't matter if we're talking about toddlers or people in their twenties, thirties, or forties. This is the one category where it's more about them, than it is about you. And in age appropriate ways, and by the way, Sharsheret has information on how to talk to children, again, toddlers, teens, adults, about cancer in developmentally appropriate ways. But in age appropriate ways, you need to let them know that they are not responsible, that cancer is not contagious, that it's okay, whatever they're feeling is okay: angry, sad, scared. That they will always be cared for and that they will always be loved. And that's the message to share with children or grandchildren. Again, no matter the age.

Melissa Rosen:

I'd say it's not fair, amongst so many of the things about cancer that are not fair, it's not fair that these are not easy conversations. You're sharing difficult, private information, and it can be draining. It can be really draining. And actually I know several people who have shared with me that they had to limit the number of conversations or disclosures they had at any given time. They were simply not able to speak to more than one or two people a week to share. It was just too difficult for them. And, in some cases, they told a couple of people, but actually chose to appoint a proxy, what we might call a chief information officer, a CIO, someone who can do the sharing for you, that's not outsourcing telling siblings or children, but the community, or friends.

Melissa Rosen:

And there are lots of ways someone can do this. It can be done in person or by phone call or by email. It can be done by online sites, such as CaringBridge, and that same type of online site, like CaringBridge, or Take Them A Meal, allows you to share continual updates, whether they're from you or your chief information officer, both of those sites, have space to share, not just I'll take this person a meal, but to share what's going on. And it could be everything from, a thank you for the support you've gotten, to I want you to know surgery went well and I'm recovering quickly, to chemotherapy was challenging this week, and my family could use some meals or company. Sharing a diagnosis or coming out with cancer can be an evolving process, and it may change, not only with who you tell, but your own emotional and physical state.

Melissa Rosen:

So I want to pivot a little bit and talk about dealing with reactions. I shared with you that personal story of how I started thinking about this, and no matter how well you plan a conversation, it may well be difficult and may well be awkward. The recipient of your news will have their own concerns and emotional reactions. Cancer stirs difficult emotions in all of us. They may have had their own past cancer experience themselves or with a loved one. Their reaction could be related to their basic level of anxiety, some people live with more anxiety than others, and obviously their relationship to you impacts the way they react. Again, it is important to remember, that cancer does really stir difficult emotions in all of us. Some people, they react just the way you'd would hope, they listen, they offer specific help, they seem to instinctively know what to do.

Melissa Rosen:

And for those of you who are recipients of the news, and at some point we likely all will be, we'll review some of the ways to react and to offer support shortly. Often, though, their reactions can be upsetting and difficult to deal with. They may start crying and you may wind up comforting someone else. They may make it about them, making comments like, "I just can't deal with this right now." A lot of times it's

asking inappropriate questions or sharing inappropriate stories. I am sure, for those of us on today's call who have been diagnosed themselves, you get questions like, "What stage are you?" Or, "What are your odds?" Really, that's not many people's business. And actually, we work with someone, one of our callers at Sharsheret, when she gets asked what stage are you? She says, "It's stage WTF."

Melissa Rosen:

So for those of you who know that inappropriate abbreviation, that's her way of telling people to back off you. You get questions like, and you do, as a breast cancer survivor myself, I am amazed at the questions people you know in passing in the community easily ask you, "Are you removing your breasts? What about your husband? How does he feel about that? Are you going to be able to have children?" Or they'll ask about your treatment plan or they'll share things that have cured people they know, "Oh, my cousin just drank a gallon of pomegranate juice a day, and within six months the cancer melted away." You can just nod your head, there's no reason to get into an argument about how pomegranate juice and acai do not cure cancer.

Melissa Rosen:

Or you'll hear stories, "Oh my sister's best friend had that cancer." And then they'll stop suddenly, and they'll realize they don't really want to share that story with you because that story didn't end well. You can be clear that you are answering questions today, simply sharing information. Just tell them, "Look, I'm not there yet. I'm not there yet. I can't have this conversation. I don't know this information. I'm not there yet." Others who you share information with will go into denial, they'll act as if nothing has changed. In doing so, often, they think they're protecting you, when we know that's not true. You can choose, in a situation like that, to bring it up to that person, if it's important to you. They may choose to withdraw or avoid you. They may be scared or threatened, have their own scary experience with cancer or upset to see you in pain.

Melissa Rosen:

I have a dear friend who was diagnosed a couple of years ago, with breast cancer. We went out for coffee, she was sharing with me that so many of our friends had reached out and asked her how she was, what they could do, but there were two of our friends who hadn't said a word. And I said, "Well, they must not know." And she said, "No, no. They know." I said, "Well, they must have talked to your husband and just didn't want to bother you." Nope, they hadn't reached out to her husband. You know what? She said to me, "I know I should not be wasting my time on this right now, my energy on this right now, but I honestly don't know if I can let go of the hurt." And I said to her, "Their reaction is not about you. They're upset on their own right. They're sorry to hear. And they haven't figured out how to deal with it yet."

Melissa Rosen:

And, very often I tell people, you don't have to craft the perfect response, but you just can't ignore it. You can't choose not to acknowledge it. But if somebody has ghosted you in that way, you have two options: you can reach out and ask for help, or you can choose not to expend the energy and let it go. There will be people who will drop out of your life because of cancer, but there will also be people who you would never expect to be there with wonderful, amazing amounts of support. In general, what can you do both to deal with the issue and protect yourself? It depends on your relationship to the person.

Melissa Rosen:

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Remember, they don't mean to be hurtful, their brains are going temporarily haywire as they process your diagnosis. You can acknowledge and respond to their feelings, and then when appropriate, move on and not linger. You can say things like, "Look, I think we both find this awful." Or, "I know you're worried about what can happen, so am I." Try not to compete with their feelings, it is your experience, but they are just processing right now, like I just said. Perhaps the most important tools you have the following sentences, and these are sentences you can use, these are responses you can use at any time and use them frequently, these are like a super power while you're dealing with cancer: 'Thank you for asking, but I'd rather not discuss that right now.', 'Thank you so much for your concerns, but I need to focus on something else today.', or simply, 'Today's a cancer free day. Let's talk about something else'.

Melissa Rosen:

By the way, you can ask to continue the conversation later, if you're being pressured to discuss details before you're ready, or you're finding it difficult to deal with the person's reaction, you can say, "You know what? Let's talk about this next week or in a few weeks, when I settle down a bit." Before we do a little Q and A, I want to recap, because these are some important facts. The decision of if and when and what to disclose is yours. It can change based on the nature of your cancer experience, you could share, and then not share more information, you can share with some people and not others, you can share some information with people and other information with other people. Some people, through no faults of your own, but because of their own issues, fears and concerns, will disappoint you. They will gossip, ignore the news, or even disappear.

Melissa Rosen:

To the best of your ability, let that go. Ignore it if you're able, or at least until you are through with active treatment and you can come up for air. Some people, even those you didn't anticipate it from, will rise to the occasion, allow you both physical and emotional support. You will be both overwhelmed and absolutely grateful for their support. I do want to share some tips for the rest of us, if there are caregivers here, or information you might share with the people around you, listen, I hope this isn't true, but the statistics do indicate that at some point we will all be the recipient of the news that someone we know has been diagnosed with cancer. We may be shocked, scared, or even relieved to have a diagnosis after a time period of concerning symptoms.

Melissa Rosen:

If someone shares a diagnosis with you, know that it is a deeply personal confession and treat it with the according respect. Listen, acknowledge the diagnosis. Cancer can be isolating, frightening, overwhelming, share your concern. Again, cancer can be isolating and frightening, overwhelming even for you, but it's never okay, like I said before, to not acknowledge a diagnosis, it is perfectly okay to say, "I don't know what to say." But at least that way you're acknowledging the diagnosis. Follow their leads and validate their feelings. They may need to speak about something other than cancer, in this case, maybe it's time to watch a movie, share a little harmless gossip, go for a walk. They may want to limit their conversation to logistics, if that's the case, they're sending a signal they need help organizing. So help organize.

Melissa Rosen:

But please do not ask someone who's dealing with cancer, 'How can I help?' That puts the onus on the patient themselves, and the best thing to do is to ask with concrete examples, 'Can I bring you a meal on Thursday? If it doesn't work for Thursday, it's freezable'. 'Can I send my teen over to help your kids with

homework? Do you need a ride to treatment? Do you need something from the grocery store?' Things like that. It's so much easier to say, 'Yes. Thank you.' Than to say, 'Actually I could really use some meals.' Or, 'I don't have a ride to chemo next week.' So much easier. They may want to talk about their diagnosis, and if that's the case, let them vent their fears, their frustrations, but don't try and solve their problems because you can't. But what you can do is listen, be there. Don't let them feel or become isolated. By the way, as caregivers, if appropriate, I encourage you to get support for yourself, caregivers of any type, I'm not just talking about spouses or parents or adult children here, but friends, colleagues.

Melissa Rosen:

Caregivers of any type may need help processing their own feelings and knowing the best way to help a friend or colleague or loved one. And Sharsheret actually has a program specifically for caregivers. Listen, in the end, sharing difficult news is painful, but we should not let our reactions compound a patient's difficult reality. And if we're the one doing the sharing, it can be scary, perhaps even as scary as the diagnosis itself, I know I felt that way when I had to tell my children each time. But we can not control a person's reaction or take it personally. So I hope that in the 30 minutes that I spoke, I was able to share some information that was, is, would be helpful-

About Sharsheret

Sharsheret, Hebrew for "chain", is a national non-profit organization, 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 four offices (California, Florida, Illinois, and New Jersey), Sharsheret serves 150,000 women, families, health care professionals, community leaders, and students, in all 50 states. 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, more than 15% of those we serve are not Jewish. All Sharsheret programs serve all women and men.

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