

# Inaugural Book Club with Letty Cottin Pogrebin

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## Inaugural Book Club with Letty Cottin Pogrebin

Melissa Rosen:

Good evening. I want to thank everyone for joining us today for Sharsheret's Inaugural Book Club program. I am pleased to share that we have several community partners joining us here on tonight's program. JOFA, or the Jewish Orthodox Feminist Alliance; Reconstructing Judaism and Ritualwell; SVIVAH, a diverse collective of Jewish womanhood; Women's League for Conservative Judaism, and Women of Reformed Judaism. We are particularly proud that these diverse organizations have joined together for this important program.

Melissa Rosen:

My name is Melissa Rosen. I am the director of training and education at Sharsheret, and I will be moderating today. Before we begin, I have a few housekeeping items to share.

Melissa Rosen:

This webinar is being recorded and will be posted on Sharsheret's website along with the transcript. The participants' names and faces will not be in the recording. You may have noticed that all participants were muted upon entry. Please keep yourself muted throughout the program. We recommend that you keep your screen on speaker view, this will enable you to see the presentation clearly, and you can find this option in the upper right hand corner of your screen.

Melissa Rosen:

We received so many insightful questions before tonight, and expect additional questions now. Please use the chat box, which you can access from the bottom of your screen, and we will do our best to address all questions.

Melissa Rosen:

For those of you who are new to Sharsheret, and a reminder to the others, Sharsheret has been providing telehealth services to the breast and ovarian cancer communities for more than 20 years. And although we could never have imagined the world as it is right now, through our services, we have been preparing for this moment and continue to be there for each and every one of you.

Melissa Rosen:

Among the many free programs and ways to receive support from Sharsheret to help women and their families navigate different aspects of a cancer experience, I want to highlight one tonight that may be of particular interest for those on today's webinar.

Melissa Rosen:

Our Spungen Foundation Family Focus Kit provides wonderful resources to caregivers, to those who support someone facing breast or ovarian cancer. Caregivers can speak directly and confidentially with one of our skilled social workers, with personal questions, and request free caregiver information, and a packet that includes all sorts of resources from Sharsheret and other cancer organizations to help you understand the diagnosis and treatment of breast or ovarian cancer and the support options available to you as a caregiver.

Melissa Rosen:

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As we move into tonight's webinar itself, I want to remind you that Sharsheret is a national not-for-profit cancer organization, support and education organization, and we do not provide any medical advice or perform any medical procedures. The information provided by Sharsheret is not a substitute for medical advice. Always seek the advice of your physician or a qualified health provider with any questions you may have regarding your medical condition. Okay.

Melissa Rosen:

It is our honor today to have author, activist, and breast cancer survivor, Letty Cottin Pogrebin join us.

Melissa Rosen:

Letty is the founding editor and writer for *Ms. Magazine*. She won an Emmy for her work on the groundbreaking *Free to Be You and Me*, which was a children's book, record, and TV special. And she is the author of close to a dozen fiction and non-fiction books, including *Deborah, Golda, and Me*, and tonight's focus, *How to Be a Friend to a Friend Who is Sick*.

Melissa Rosen:

I'm also excited to share that, later on tonight, we'll be raffling off a signed copy of her book. She's currently working on her 12th book, *Shanda: A Memoir of Shame and Secrecy*.

Melissa Rosen:

I had the opportunity to reread parts of your book last week, Letty. What struck me was just how relevant it still was today, if not more so than when it was originally published in 2013. It's amazing. Can you talk a little bit about what, in your personal experience, led you to writing this book?

Letty Cottin Pogrebin:

Yes, first of all, hi, everybody. I love seeing all your faces, and some of the names I recognize as well. I wrote this book because I wanted to read a book like this when I was in treatment. I really was shocked by how many of my friends were kind of awkward around me, didn't know what to say, said really stupid things, said upsetting things, didn't come through for me. The ones I wouldn't have expected to be warm and loving and responsive were, and the ones I would have expect to be warm "fumfed". They carried on. They kind of made me feel it was my fault. All kinds of bizarre reactions.

Letty Cottin Pogrebin:

And I was sitting in the Memorial Sloan Kettering waiting room where I spent six weeks of my life, and I Googled, "Friendship and illness," to see how to respond to the people who didn't seem comfortable dealing with me. You know? It suddenly became my problem, and there weren't books that were able to answer those questions.

Letty Cottin Pogrebin:

There were a lot of books on how teenagers should treat their friends if their friends are ill, which I thought was kind of reassuring, but surprisingly, not for grown ups.

Letty Cottin Pogrebin:

So, I decided I would write one. And then I said, "Well, you know, I'm in treatment. I can't go running around the way writers and reporters are supposed to, interviewing people all over the country, getting

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a broad sampling and all of that. So, maybe it's not a great idea." And then, I looked around the waiting room, and there at Memorial Sloan Kettering was my sampling. People of every age, women and men, interestingly enough, caregivers who had come to accompany people to their treatments, and people who had flown in from all over the country, and some from all over the world.

Letty Cottin Pogrebin:

So, I started interviewing the people in the waiting room, and that was the genesis of the book.

Melissa Rosen:

Amazing, amazing. Can you-

Letty Cottin Pogrebin:

The amazing thing, Melissa, and everybody else, is ... Let me just cut to the chase. The message of my book is the new illness etiquette is honesty. And I was stunned by how responsive and open people were the minute I started explaining what I was up against, how I felt, what kind of pissed me off about being sick, honest, my anger, everything else that people have been thought to repress, and immediately, the response was, "Let me tell you about mine. Let me tell you about a friend of mine. You won't believe what a friend of mine said!" Or, "You won't believe the most wonderful thing friends of mine have done to make it easier for me."

Letty Cottin Pogrebin:

And so, the waiting room was a kind of gift that kept on giving because every day it was a different group. None of us scheduled for the same times. I had a particular treatment room, but I was scheduled for different times of day and so were others, so I was constantly seeing a new round of people, and I just went right up to them and said, "I'm writing a book about friendship and illness. Can you tell me how your friends have responded? What's been helpful? What's made you cry? What's surprised you? What about men and women and how they respond?" And before you knew it, it was all about everything. It was all about everything.

Melissa Rosen:

Sounds like people were almost looking for a chance to share.

Letty Cottin Pogrebin:

Yes. And I went beyond the waiting room because, obviously, six weeks isn't enough to write a book. And so, I spent many, many months just seeking out people who weren't like other people that I had already interviewed. I mean, I did not interview anyone in the waiting room who had lived through the death of a child. I was in a cancer place.

Letty Cottin Pogrebin:

But a lot of the people had had heart conditions, or had lost a spouse, or a friend, but I really wanted, for example, in this book, to talk to someone who had lost a child because I could not imagine anything harder to live through, and I hadn't the experience of how to be a friend to someone who had lost a child.

Letty Cottin Pogrebin:

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So, I went looking for things I didn't have, but other than that, I seem to kind of encounter people who had every possible kind of experience: mental illness, dealing with Alzheimer's. So, I know that Sharsheret [inaudible 00:10:10] breast cancer, and ovarian, and uterine cancer as I understand it, but I think all of us in this call-in in our life have been through a lot of other stuff. So, it becomes, really, a meditation on how to deal with stress and what to expect from one's friends.

Melissa Rosen:

So, let me ask you. I know that many people, including myself, who are on the webinar tonight have been truly hurt by people's reactions as you talk about, or lack of reaction, to a difficult diagnosis or situation. Do you have any advice for getting beyond that hurt? And does it make sense to share our pain with those who have hurt us?

Letty Cottin Pogrebin:

That's very well put. Several things were revelatory for me, let me put it that way, that very often people either spoke in platitudes and cliches because we don't really know the right thing to say, or they just blurted something out because they were shocked.

Letty Cottin Pogrebin:

I should probably back up and say the hardest thing for me to do, at the very beginning, was decide who to tell, because you open yourself up to months and months of having to kind of update a lot of different people the more you tell. And then, you have to live through it many times over because of that. And I could kind of foresee that I would really want, at some point, to stop being cancer girl, that it was very helpful to me, at first, to have everybody suddenly say, "Oh, I don't know if you realize it, but I had cancer 35 years ago, and this is what I learned." That was helpful.

Letty Cottin Pogrebin:

But when somebody would say, "Well, if you end up needing a mastectomy, at least you're married." You know? This was not helpful. This was not in the least bit helpful. And on the other hand, when I had two of my friends who had, within, let's say, five years, had breast cancer and they became my walking partners. And when I freaked out, and when I didn't know what was going to happen, and I didn't understand what was happening to me, and I couldn't decode all the language in the very beginning, they were invaluable because I could ask them anything.

Letty Cottin Pogrebin:

And that's when I said to you earlier, "Honesty is the best etiquette of illness," because they gave me permission to ask them anything. And if you can find among your friends ... And let's face it, Jewish women, one in eight of us have breast cancer. I'll never forget a dinner party in my house, 10 couples, five women, four of us had had breast cancer.

Letty Cottin Pogrebin:

So, it's not as if this is, quote, "The C word," which was my mother's generation. We can talk about this now because we know so many people who have had it, people who have struggled, people have had every version of it, and people who are thriving. And if you can find honest friends who will walk you through it, who are willing to revisit their misery, their fears ...

Letty Cottin Pogrebin:

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And I tell, in the book, about my friend ... I had two friends, Lynn and Joyce, both journalists. One at the *New York Times*. One was the editor of *Working Woman*. And they had each had it in recent times, so stuff was fresh in their mind. I asked Lynn, "How did you tell your kids?" I have three kids. They were all out of the house.

Letty Cottin Pogrebin:

I got my cancer when I was 70, by the way, so my kids were well-grown. And I said to Lynn, "I have really made a mess of it with my children. I told them by email," because I was terrified to hear their voice or have them hear my voice. Or, to call a family meeting, I thought it would be terrifying for them to hear that I'm calling a family meeting. Why am I calling a family meeting?

Letty Cottin Pogrebin:

It was the day after Yom Kippur, in 2009. I hadn't even committed a single sin, and I got my diagnosis. And I know my children. I know they couldn't tolerate not knowing, and they're older people, human beings. But I made a terrible mistake doing it by email. They felt so dissed, you know? They felt like I was making them like any other group of friends, because I did, I told my other friends by email too.

Letty Cottin Pogrebin:

It's just that I was protecting myself from falling to pieces. And I was afraid that I would see their reaction, it would make everything worse. So, my friend, Lynn, just reassured me. She said she did the same thing, and her kids survived it and forgave her.

Letty Cottin Pogrebin:

You know, we don't necessarily do the right thing.

Melissa Rosen:

Of course. We're all human. But you know, you bring up an interesting point. In terms of caregivers, some of them have very close relationships to us. They're our children, our partners, our parents. Some are our dear friends, and sometimes even neighbors and colleagues take on that role. But as caregivers, many of us feel awkward or even get tongue tied in the presence of a friend or family member who's facing a serious illness.

Melissa Rosen:

Your book offers a lot of wonderful advice about what to say and what not to say. Can you share a few examples of words that are comforting and maybe some of those better left unsaid?

Letty Cottin Pogrebin:

Yeah. You froze, Melissa. Can you all hear me? Just nod if you can hear me.

Melissa Rosen:

Did you hear the list of questions?

Letty Cottin Pogrebin:

Yeah. I did hear the question, but you had frozen. I'll tell you the first three things not to say, because, otherwise, everything is so individualized. But oddly enough, "How are you?" Is a really hard thing for us

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to all hear. I don't know where all of you are in the process, but when it was the worst time for me, the last thing I wanted to answer was, "How are you?" Because I knew if I started to tell them how I really was, I would give them too much information.

Letty Cottin Pogrebin:

If I was with them, I would see their eyes glaze over. If I was on the phone, I would hear pots because they would be making dinner, or sweeping, or doing something else while I was going on and on about my Oncotype and my clean margins. Excuse me. So, "How are you?" is not a useful question.

Letty Cottin Pogrebin:

I ended up liking people who said things like, "What's new?" "What's new" is so wide open. You know, it'd like our Yiddish relatives used to say, "So new?" And that's basically very open-ended for me.

Letty Cottin Pogrebin:

The other thing is, "You look great." I came to loathe that line because I knew-

Melissa Rosen:

[inaudible 00:17:46] in the chat, yeah.

Letty Cottin Pogrebin:

Yeah, because I knew that I wasn't asked every single day by all my friends, "You look great," or told, "You look great." So, this was a measure of me not looking like myself. This was then cheering me up. This was totally transparent and not useful.

Letty Cottin Pogrebin:

The third thing was, "Oh, my G-d." When a teenager says, "Oh, my G-d," it means "Oh my G-d, I just got the best sandals." Or, "I just saw a great movie." When a person my age says, "Oh, my G-d, it does not bode well." So, I did not want to hear, "Oh, my G-d."

Letty Cottin Pogrebin:

Now, as far as what I did want to hear, it's what I said to my friends, which was, "May I tell you what's helpful and what's not?" You know? And I wish they had said, "May I ask you what's helpful and what's not?" Because then it would give me permission to deal with that, you know?

Letty Cottin Pogrebin:

In other words, if someone had said to me, "Would it be helpful if I asked you what I could bring instead of bringing a Zabar's basket full of stuff?" Or, just bringing a plant because I would have said to someone who said that, "You can ask me. I know you're going to bring something. You're one of those people who brings when they come to a sickbed. But what I really would like is lamb chops and a brownie," because that's my comfort foods when I was going through the tough stuff.

Letty Cottin Pogrebin:

I wanted lamb chops, my favorite food, lamb chops. Pesto pasta, and a brownie with walnuts. And you know, if people asked me that, I would have been so happy to tell them. If they had asked me, "What

haven't you read?" Instead of bringing me what they thought maybe I would read or maybe regifting a book.

Letty Cottin Pogrebin:

If people who would have give me something very expensive like a Zabar's gift basket. I don't know if you know what goes in them, but it's like \$150, I would have preferred a certificate for a massage, frankly, for creature comforts. That's what we need most when we're facing our own mortality, or in pain, or scared to death. Just to be able to zone out on a massage table before I was walking around with a drip thing in my chest, that would have been ... To be able to say that, to say to people, as a patient, "May I tell you what's helpful and what's not? May I tell you when to come and when to leave? May I tell you what I like and what is really not helpful." That permission would allow a relationship to happen where the friend is not always second guessing.

Letty Cottin Pogrebin:

"Oh, my G-d! I went to the hospital room, and it was full of bouquets of flowers, and I sent flowers. Why didn't I think of something else?" So, when you're thinking about a visit, you might ask the partner or the person that is taking care of that person, "What's the best time of day? And maybe I could call in advance? And would that be okay? And if I bring rugelach, will I be the 12th person to bring rugelach?" You know?

Letty Cottin Pogrebin:

Just that kind of individuation, I think, and permission to say anything and ask for anything is what connotes a really useful and reassuring and comforting and energizing and nourishing friendship.

Melissa Rosen:

That's great. And I love that I'm seeing in the chat, people are sharing their own experiences of what has been helpful for them, and what have they hated too.

Letty Cottin Pogrebin:

I see. I forgot to look in the chat.

Melissa Rosen:

No, that's okay.

Letty Cottin Pogrebin:

I had a friend who sent me a joke a day. I loved that. Someone in the chat said, "I asked people who wanted to call to tell me a joke so I had a chance to laugh." So, I loved it. I got a joke a day, and my friend, Marlo Thomas ... You mentioned *Free to Be You and Me*, so we'd known each other for more than 40 years. And when I was going through this, Marlo sent me pretty much a joke a day.

Letty Cottin Pogrebin:

And my favorite one was, she said this man was in a terrible accident and he was wrapped up in bandages, head to toe, everything covered in bandages, except one eye was out. And the doctor came in and looked him over and says, "You know, I don't like the looks of that eye."



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Melissa Rosen:

Yeah. Very uplifting, right?

Letty Cottin Pogrebin:

I love that.

Melissa Rosen:

That's a good one. That's a good one. Let me ask you another question. At Sharsheret, sometimes we find that people are reluctant to take on the title of caregiver. For example, when a spouse or partner is dealing with the day in and day out, an adult child or a friend may feel it's not their place to have that title. How would you define caregiver? And then, secondly, how do you feel about the term caregiver?

Melissa Rosen:

I just did a program last week and somebody said, "I hate the term caregiver. I'm not caring for my daughter. She's an adult. I use the term lovegiver." So, how do you define ... You know, a good definition of caregiver, and is that phrase a comfortable one for you?

Letty Cottin Pogrebin:

I don't like that phrase myself. The alternative to me, that I hear in my ear is, "caretaker." You know, which is kind of like doing your lawn. I think all of those titles are for other purposes originally, and so, they don't fit us.

Letty Cottin Pogrebin:

But helper doesn't always work. Companion feels a little old lady in a shawl. I don't know if we need language like that. It's Marcy, who's hanging around and helping me do my shopping. Or, some way of not making a genre out of it, if you know what I mean.

Melissa Rosen:

That's interesting.

Letty Cottin Pogrebin:

But I do think while we're on the subject of caregivers or whatever we want to call them, is they very often need a friend. The stress on caregivers, since we haven't thought of another title, or helpers, or companions, or partners, is at times worse than the stress on the patient because the patient knows how she feels and the caregiver has to sometimes guess, or anticipate.

Melissa Rosen:

So, that leads to my next question, which is how do we support not just those facing illness but primary caregivers who are really getting a double dose of all of this?

Letty Cottin Pogrebin:

Yes. Well, you know, they could use a massage also, but probably most of all, what they need is time off. So, if you can relieve them. If you can say, "Why don't you just go out to lunch?" Or, "Why don't you

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take a couple of hours, a walk in the park?" Or run, or "Go to your gym. I'll handle this now." That would be the best gift of all.

Letty Cottin Pogrebin:

And also, a caregiver told me that ... Because, as I said, I interviewed the people who accompanied people in the MSK waiting room. So, they were very often the caregivers, and they said, "Sometimes people forget that besides this person in my life who I'm taking care of, I have a sick mother over here, I have a kid I'm worried about, I have a whole life. My life is not just this person, as much as I might love her or be paid for it."

Letty Cottin Pogrebin:

And I think we sometimes forget that, that the person who's caring for the person we care about has a life.

Melissa Rosen:

Yeah, absolutely. You know, we got a question from our community partners, SVIVAH, and it's a great question that follows this perfectly, which is, cancer or illness in general can feel so very isolating. In addition to the support that someone receives from family and close friends, some of us are lucky enough to get additional support from community, which, of course, does not only support the patient, but relieves the caregivers. But to you, what would great community support look like, and could you also talk a little bit about why it's important?

Letty Cottin Pogrebin:

Well, I think if you kind of enlarge what I said about my two walking friends, that's what community support does, except it does it on a broader scale and it gives you probably more people in your life who have something closer to what you have.

Letty Cottin Pogrebin:

There came a moment where I felt the last person I could be helpful to was somebody who had a double mastectomy or who was in chemo because I came out the other side of this much faster than somebody who had a mastectomy or chemo, and there was nothing I could give except my own sense of what I went through. I couldn't imagine ... It's so impossible to imagine worse than what I went through, because what I went through, I thought was hard enough. So, I found it hard to imagine myself being helpful. In a larger support group, you can make alignments based on something closer to your own experience.

Letty Cottin Pogrebin:

I will say, however, and I don't know if Sharsheret is going to love this-

Melissa Rosen:

Uh, oh.

Letty Cottin Pogrebin:

... but there were people who told me they hated support groups because it brought them down.

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Melissa Rosen:

Right.

Letty Cottin Pogrebin:

And if you don't organize it in a way that [inaudible 00:28:37] not people crying, and weeping, and feeling they're going to die within a month, keeping those people from pulling down the people who just got a diagnosis. That's really hard. So, I passed that along to you because I was told that a couple times.

Melissa Rosen:

Yeah, and it's valid. I think Sharsheret would wholeheartedly agree. For some, support groups are the best, and for others, one-on-one support. Everybody is different, and that's really-

Letty Cottin Pogrebin:

[crosstalk 00:29:06], yep.

Melissa Rosen:

Really important.

Letty Cottin Pogrebin:

I want to pick up on somebody ... I said I can't get rid of the list of participants, so it's hard for me to see the chats once at a time. If you have any suggestions for how to move the participants out of the way.

Melissa Rosen:

Yael, do you have an easy way for Letty to do that?

Letty Cottin Pogrebin:

I would pay you to call me Letty for the rest of my life because nobody says it so beautifully. Thank you.

Melissa Rosen:

Well, you're more than welcome.

Letty Cottin Pogrebin:

I have to learn to use my ... call myself that.

Letty Cottin Pogrebin:

Anyway. Somebody here said something that I wanted to talk about, and now I can't find it, but it was something like, "Be strong," or "Be positive," or "Be tough."

Melissa Rosen:

"You're so brave."

Letty Cottin Pogrebin:

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Okay. It was be brave. It disappeared from the chat. Military metaphors were among my least-favorite expressions of uplift, supposed uplift. "Battling." I don't like "Survivor," honestly, because a survivor, to me ... I mean, I was a child of the Second World War, a survivor to me is a survivor and not a person who got through breast cancer. But again, the language is ill-equipped.

Letty Cottin Pogrebin:

I am ill-equipped to find any better language than the one we have because I don't want us to be called victims. We're not victims.

Melissa Rosen:

Well, you're right-

Letty Cottin Pogrebin:

We got through it. But-

Melissa Rosen:

[crosstalk 00:30:34]-

Letty Cottin Pogrebin:

... I don't want to be told, "Be brave." I don't want to be told to fight. I don't want to be told that I should stay positive. I didn't want all that. They were kind of cheerleader lines, you know? They were not honest exchanges of concern.

Melissa Rosen:

Yeah. So-

Letty Cottin Pogrebin:

[inaudible 00:31:02].

Melissa Rosen:

Letty, right now, you're a little frozen, but there were just instructions in the chat box about how you can change the view. And while you're doing that, I just want to point out that-

Letty Cottin Pogrebin:

Oh, yeah. Thank you.

Melissa Rosen:

... while Letty was concerned that Sharsheret wouldn't like to say that support groups are not necessarily the best thing, I just want to point out that Sharsheret doesn't offer support groups. We offer one-on-one support. So, the partners we work with have them, but we offer one-on-one, and customized and personalized support.

Letty Cottin Pogrebin:

Oh, good.

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Melissa Rosen:

I want to ask you a couple more questions before we get to some of the questions that came in through our registration and through the chat box.

Melissa Rosen:

So, one of them is, could you talk for a moment about how being Jewish impacts the way you choose to caregive in your life, and is there also an impact to how you received care?

Letty Cottin Pogrebin:

Melissa, please repeat that because you froze.

Melissa Rosen:

Sorry. So, I wanted to know how does, or if it does, if being Jewish impacts the way you choose to caregive in your life, and did it impact the way you received care?

Letty Cottin Pogrebin:

It impacted the way I received care from some people who are in touch with these matters, who are involved in meditation, who are involved in ... Rachel Cohen was a very good friend of mine. I mean, people who interacted with Rachel, interacted out of neshama, of a Jewish tradition, out of an understanding that healing is possible through many, many different routes.

Letty Cottin Pogrebin:

When I was in the waiting room, the most interesting person I interviewed was a Hasidic man. I write about him in the book, and I will never forget him. He wore a shtreimel, he had payos, he had a full-on coat. And he was carrying a book the title of which was Shoah, which I read in Hebrew.

Letty Cottin Pogrebin:

And I opened the conversation with him and I said, "I'm doing this book, and I'd like to interview you." He wouldn't speak to me. He paid me no attention, maybe because I was wearing a tank top and blue jeans. I could kind of excuse that. But I was really determined, so I said to him, "Look, you're reading a book. I'm writing a book. We're the people of The Book," I finally got a laugh out of him. I said, "I just need to know, I will never get into your community to be able to do these interviews, and I need to know: What's it been like in an orthodox community where bikur cholim is such a big thing, and maybe you know that the Talmud says "1/60th of your pain is relieved with each visit by a sick person." And all the things that we know about Judaism and observing Judaism.

Letty Cottin Pogrebin:

And I said, "What's it like? You must get so much love and help." And he said, "Nobody knows." He said, "I can't tell [inaudible 00:34:35] my wife is the only one, and Hashem. The only ones who know." I said, "How could that be?" He said, "Because I could never make a shidduch for my daughters if they knew there was cancer in my family."

Letty Cottin Pogrebin:

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So, that was a real stopper for me. That was something ... I was romanticizing what Judaism does for us all, and suddenly, he's telling me he couldn't reach out to anybody. In fact, it's a shanda he would have to hide. So, there's two sides to our coin.

Melissa Rosen:

Right. But thankfully, many of us have had very different experiences within our community, and I've heard many stories of it being very wonderful in different faith communities.

Letty Cottin Pogrebin:

I'm sure, I'm sure.

Melissa Rosen:

But let me-

Letty Cottin Pogrebin:

I'm sorry that that was his experience because [crosstalk 00:35:29]-

Melissa Rosen:

Yeah, yeah. Let me ask you one other question that came in from one of our community partners, from Women of Reform Judaism, and once this one is done, I think we want to start taking some participant questions simply because I don't want to run out of time. But this one we can't skip, which is: Really, caregiving has taken on an entirely new dimension in the age of COVID-19. Can you share some stories or information that might be insightful or instructive based on today's situation?

Letty Cottin Pogrebin:

I'm 11 years out from my diagnosis, and I have tried very hard to totally embrace life as if I never had cancer, although we all could have it the minute after our treatment's finish. We could also get it all over again. We all know that. We're all realists.

Letty Cottin Pogrebin:

So, I can't say what in today's world I would do, except to say what has been really helpful to me with my friends over this time, because I haven't seen anybody. I left New York City on March 25th, and my husband and I are up here and lucky enough to be in the Berkshires. And we've Zoom'd people, and those have become very intimate conversations.

Letty Cottin Pogrebin:

I mean, right now, I'm looking at dozens of you, and I don't know you, but if I was looking at two other friends, or four other friends, I could be as honest as I would be if I were in the room. And I would be glad to be as helpful as I could from a distance. So, I'm not the person to answer this based on personal experience except to say that if it works for friendship in general, it's going to work for friendship in illness.

Melissa Rosen:

Okay. That's good advice. That's very good advice. And actually, wonderful to hear that somebody's part of an observant community in her city and her city was very, very helpful.

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Letty Cottin Pogrebin:

Oh, I'm sure that this man's experience is unique or is rare, but I have never forgotten it because of the pain. And you talked about isolation, because isolation was total.

Melissa Rosen:

Absolutely.

Letty Cottin Pogrebin:

I see here that somebody said [inaudible 00:38:03] attitude. What am I supposed to do? Just lay down and give up? I'm not always positive. I've been angry, sad, et cetera.

Letty Cottin Pogrebin:

Again, if we have to be protective of our friends and not show them our anger, we might as well not see them at all or talk to them at all. Very often, I discovered by visiting a friend of mine who had a very serious back operation, I realized ... I had called in advance. I thought I did everything right. I called in advance. I brought the best cookies in New York, which is from Levain Bakery. I thought I was being as careful as anyone could be, and then I left. My husband and I went, and we left afterwards, and I suddenly realized he was wearing freshly ironed pajamas. The bed was really neatly made.

Letty Cottin Pogrebin:

His wife had brought a chair over. She had made coffee. She had to leave the room to make coffee. They had moved the chairs. I realized that my visit had discombobulated his day in more ways than I could have anticipated. He must have been in crinkled pajamas, or a t-shirt and a pair of underwear. She might not have had to neaten up. She didn't have to go and make coffee.

Letty Cottin Pogrebin:

So, there are moments when you need to kind of take in the bigger picture, not just your good impulse, not just your best intentions.

Letty Cottin Pogrebin:

And what occurs to me when I remember that is a friend of mine said that she went to visit a sick friend of hers, and she fit it in on her way to the gym, and she was kind of proud of herself because the hospital was out of the way. But she arrived in her sweat pants and workout clothes, and the sight of her in this uniform of normal life was so depressing to her sick friend that she not have visited at all.

Letty Cottin Pogrebin:

And that's what we don't necessarily consider. We're thinking, "I really want to get up to see Anne. She's in the hospital. And I'm just going to go out of the way, and I'm going to go out of my way and get to the hospital." And you're kind of pleased with yourself. You feel good about that. And then, what you did was hurtful. We have to just enlarge the prism.

Melissa Rosen:

You just have to remember what's best for the other person, even if it means curving wonderful impulses.

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Letty Cottin Pogrebin:

Mm-hmm (affirmative).

Melissa Rosen:

We received so many meaningful questions from participants as they registered, and tonight, through the chat function. So, two of my amazing colleagues, Nancy Cohen, and Deborah Litwak, both program coordinators from Long Island and Florida are going to join us to see if we can get some of those answered.

Nancy Cohen:

Thank you. Letty, I'm going to start with a question that you addressed a little bit, but I think it's an excellent question and worth elaborating on. So, someone shared she's not only a caregiver, but a patient herself at this moment. Can you offer some advice that might help her in this difficult situation?

Letty Cottin Pogrebin:

Who's caring for you? I mean, this is like a triangle, and everyone has to kind of be aware of the other sides of that triangle. So, don't be brave. You know, you could just emblazon that over your desk, "Don't be brave." Confess, share, explain, "I'm also going through something, so I may be a little short-tempered at times. I may be tired. I may be [inaudible 00:41:55]."

Letty Cottin Pogrebin:

Again, I've never found honesty to be a bad thing, even with people who are dying, maybe especially with people who are dying. I know you're not dying, but I always go to the furthest extreme of whatever I'm saying.

Letty Cottin Pogrebin:

When a friend of mine was dying, I called her. We were pretty far apart in miles, and so, I called her often. And I said, "What do you feel like talking about today?" She said, "Dying. No one will let me talk about it." So, the same is true for a caregiver who's sick. You have to be allowed to talk about being sick too and what you're going through.

Melissa Rosen:

That's great, thank you.

Deborah Litwak:

Thank you, Letty. Another question came in. Someone shared a question about someone with a chronic illness, and surely, that can apply to those living with metastatic cancer.

Deborah Litwak:

When the need for supporting caregiving is on-going, how do we change what we offer, or even, how can we, on the other side, expect the continued care from caregivers?

Letty Cottin Pogrebin:



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Yeah. And not just from caregivers, but continued attention from our friends, empathy from our friends. Over the long haul, some people are really good in a crisis. They can come through for you. They'll just stop everything for you. They'll do all the right things, and they'll come like gang-busters to be helpful.

Letty Cottin Pogrebin:

But if you have a chronic illness, if you have Crohn's Disease, or if you have metastatic cancer, or if you're dealing with something you don't know the end of, very often, people kind of check out. They cannot be with you for the long haul. Or, if they don't see what's wrong with you. You know, they don't see what's wrong with you.

Letty Cottin Pogrebin:

Again, I use something like Crohn's, or people in the early stages of Alzheimer's. If people don't see an ailment, they very often forget you've got one. And if you're going about your business, if you're going to work, if you're making meals for your family, people can forget what's going on in the interior world that you live in.

Letty Cottin Pogrebin:

I would simply advise somebody who is feeling ill-treated or inadequately-treated in that situation to say, "Look, I know it's really hard to realize that this is the second year I'm in this situation, and I know it's hard to stick it out for me, but frankly, at this point, I can't get anything but bad vibes from you, so please back off."

Letty Cottin Pogrebin:

"Please back off. I'm feeling your impatience. I'm feeling your insensitivity. I know you love me, but something's not working for us, so back off." The person will feel guilty and terrible, but you know, you've got to save yourself.

Melissa Rosen:

Good advice. Do we have others?

Nancy Cohen:

Yeah, we do. Letty, can you speak to the issue of competition between caregivers and the primary caregiver blocking access to others that love the patient?

Letty Cottin Pogrebin:

Mm-hmm (affirmative). Yeah. I heard a lot of that. I heard a lot of that in terms of the spouse, really, from friends who felt that they had more to offer than the spouse. Generally, male spouse had more to be usefully involved.

Letty Cottin Pogrebin:

You know, sometimes we say about fathers, they helicopter in and we're there all the time, and often, the male spouses helicoptered in and felt fairly virtuous for doing what they did, and the friend had spent the day. The friend had spent the day.

Letty Cottin Pogrebin:

So, the best advice I heard from anyone was simply to set up a schedule, and that was a schedule for, in the case I'm thinking of, for 130 people who were involved in one woman's friendship circle, who divided cooking, delivering, shopping for her, taking the kids, answering phone calls, answering emails, opening her mail. This 130 people had a spreadsheet, and they simply included her husband so that he understood this was a grid, here. "You're important. She loves you. You love her, but there are a lot of people here that your wife is very dependent on right now." And that seems to work.

Melissa Rosen:

That's great advice. That's actually what we did in my family when I was dealing with it. We created a spreadsheet. Okay. Another question?

Deborah Litwak:

Yes. One more. You made mention of allowing someone to speak about what they wanted. When they wanted to talk about end of life, it was there. Is there a sensitive way, or an appropriate way, to open that conversation with someone, to ask for an open and honest conversation without depressing them or sounding morbid?

Letty Cottin Pogrebin:

Yeah. You tell them to anticipate it, if they're not really ... If that's not really what they want, you just want to open the door. You want to keep that door open. And again, if you say, "What do you feel like talking about today?" Instead of, "Do you feel like talking about end of life stuff?"

Letty Cottin Pogrebin:

"What do you feel like talking about today? Do you feel like talking about how you feel or what you're thinking? What's on your mind that wasn't on your mind yesterday?" Put it that way.

Letty Cottin Pogrebin:

There are opening lines that's literally our opening lines. They don't set the agenda. And that's what I said earlier about, "What's new?" instead of, "How are you?" And "What do you feel like talking about?" Or, "Do you feel like talking at all today? Because I'm here. I'm here."

Letty Cottin Pogrebin:

And let me say, if you only have 20 minutes to be there, tell the person in advance. That occurs to me to mention because how much time people spend with us when we're ill, or when we're in treatment, or when we're recovering, or when we just don't know what's going to happen next, sometimes a visit ... People may think that you're there for an hour and you have 20 minutes because you have to pick up the kids at school. And just, again, to be right up front. "I wanted to see you. I wanted to bring you this casserole," and you got to put your casserole on the spreadsheet or you get a lot of casseroles on Friday for the weekend and none on Wednesday.

Letty Cottin Pogrebin:

But that, again, that has to be out front. It has to be, "I can only stay for 20 minutes, but this is why I came and I wanted to see you. And I'll come back. When would you like me to come back, or should I call first?" It's really once you say, "I want to be honest and I want you to be honest with me," you never

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have to worry about these things because you're going to forgive each other if you mess up. You've already said that. You already put the ground rules out there.

Letty Cottin Pogrebin:

"I'm going to mess up. I'm going to say stuff that annoys you. I'm going to miss your signals. Please forgive me and tell me so I won't do it again."

Melissa Rosen:

That's great. That's great. We're all just human like you said.

Melissa Rosen:

You know what? Was there any other one you wanted to sneak in? We might have time for one more, otherwise, we can move forward?

Melissa Rosen:

No?

Letty Cottin Pogrebin:

Well, I liked ... Somebody said that she didn't want somebody with recommendations. I forgot the phrasing. The recommendation, you know? "Use ginkgo biloba." Or, "I swear by this doctor." Or, "The most wonderful thing that happened to me was falling into a tub full of butter." You just don't want other people's bubbe-meises or cures. You have doctors for that. You have your own reading, your own research.

Letty Cottin Pogrebin:

And I hope everybody who is in the early stages is taking somebody with them to their doctors' appointments.

Melissa Rosen:

If it's allowed these days, or getting on the phone and listening in.

Letty Cottin Pogrebin:

Yeah, that's right.

Melissa Rosen:

Absolutely. You know what? I am very cognizant of the time. As we end, I want to thank you, Letty, so much for sharing so much of yourself tonight. You've made what can sometimes be an uncomfortable situation a bit easier, and with that, hopefully more meaningful.

Melissa Rosen:

I do want to take one more moment to thank, again, our community partners, JOFA, Reconstructing Judaism and Ritualwell, SVIVAH, Women's League, and Women of Reformed Judaism. And a special thank you tonight for tonight's sponsor, the Florence and Laurence Spungen Family Foundation, for their dedication to caregiver support.

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Melissa Rosen:

Right now, a link to a very quick evaluation survey is being placed in the chat box. Please, I ask you, take a moment to complete it. Evaluations really do inform future programming. And I'm happy to announce that, later tonight, we will pick from among those who filled out these evaluations and one person will win an autographed copy of Letty's book.

Melissa Rosen:

I do want to let you know that one of the questions in the evaluation is if you're interested in having a program about supporting a loved one or creating a caring community in your community. Sharsheret offers some very meaningful programs these days, via Zoom. And so, if you're interesting in bringing this content to your local community, there's a place to ask for that. There's a place to ask for caregiver support, and a couple of other questions.

Melissa Rosen:

As we close, I want to remind you that Sharsheret's team is here for you and your loved ones. Sharsheret provides support and programs designed to help navigate through the cancer experience. All are free, completely private, one-on-one. And contact information is being placed in the chat box now, as well as will be in a follow-up email. Our social workers and genetic counselor are available to each one of you. Your health and well-being is our priority.

Melissa Rosen:

Finally, I just want to note that we have two additional book club events played. Ali Rogan, author of *Beat Breast Cancer like a Boss* will join us on January 7th. And Jessica Queller, author of *Pretty is What Changes* will join us on March 7. And information about both of these will be forthcoming.

Melissa Rosen:

Thank you again for joining us. Thank you, Letty. Please don't leave until you click the evaluation link, and have a wonderful night everyone.

Letty Cottin Pogrebin:

Thank you. Bye bye.

Melissa Rosen:

Good night.

Melissa Rosen:

I'm going to wait a second to close just so we can get people to click that link. And also, I see there's still comments, really lovely comments, coming in.

Melissa Rosen:

Can we post the evaluation link one more time? Okay. It just got posted again.

Melissa Rosen:

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And for those of you who are still on, there'll be a follow up email with a link to the recording and a link to some of our resources online for caregivers by the end of the week.

Melissa Rosen:

The next book is *Beat Breast Cancer Like a Boss* by Ali Rogan. And she's actually going to be bringing some fun friends with her, some surprising friends.

Melissa Rosen:

Sharon's iPad raised her hand. Sharon, do you want to put what you have in the chat box, if you have a question?

Melissa Rosen:

And I just want to remind the people behind the scenes to save the chat.

Melissa Rosen:

Okay. Can we post the evaluation link one final time? And then we can shut down the program. Thank you very much. And I would say, in two minutes, we can close the webinar. Everybody who will have wanted to fill it out will have clicked it already, and if they change their mind, there'll be another link in the follow-up email.

Melissa Rosen:

Okay. Wonderful. Have a fantastic night, everyone. Thank you so much for joining us and being part of this really glorious community, and hopefully we'll see you at the next book club event. Bye-bye.

## 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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