

Take It From Me: My Experience In My Own Words

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Presented By



Linking Young Jewish Women in Their Fight Against Breast Cancer

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I. Introduction

Shera Dubitsky, MEd, MA Clinical Supervisor

Shera Dubitsky: Thank you to all of you for joining us this evening for Sharsheret's teleconference, *Take It From Me: My Experience in My Own Words*.

My name is Shera Dubitsky and I am the Clinical Supervisor at Sharsheret. I will soon have the pleasure of introducing our speakers, all of whom will share their knowledge and insights into the world of storytelling, journaling, and blogging.

By joining us this evening, you all share a common interest in putting your stories and experiences into writing. The reasons behind this interest though, may differ. Some of you may want to journal your experiences in order to create a space where you can hold your personal thoughts and feelings for your eyes only. For some, sharing your experience in a public space enables you to keep your friends and family updated as to your well being and it also minimizes the need for you to repeat information. Some of you may want to document your journey as a historical piece for your children in future generations. And some of you may want to write your stories and experiences as a source of support to other women and their families facing breast cancer, and I suspect that it's probably a little bit of each.

As Jews, we are known as the people of The Book. Torah consists of the oral word and the written word and they work together, each existing only with the other. The written Torah is needed as an anchor for the oral Torah. We are commanded as Jews over and over again

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to communicate our history and our knowledge to future generations. So for example, in the Shema Prayer, it says: "thou shalt teach them diligently in two of your children."

We are commanded to annually recite the Haggadah at our Passover Seders, to hear the Megillah readings yearly as a reminder of the journeys taken by our ancestors, to learn from their experiences, to never forget where we have been, and to use it as a blueprint to where we are going.

The Torah, interestingly, was first given to women because it was understood that women would pass it along to their children. And this is our legacy as women. As a people, we are enriched by these personal examples and we look to our ancestors as role models. Dor le Dor, from generation to generation. Writing your experiences makes it real. Documenting your stories enables you to clarify your position, to know where you are to yourself and to others. Sharing your experiences allows others to benefit from your wisdom and your insights. It is a beautiful form of chessed of loving kindness, because it gives comfort. It creates a sharsheret, a link connecting women with shared experiences and backgrounds.

Sharsheret recently launched a blog at Sharsheret.blogspot.com, as a means of providing an open environment for women to share their experiences and connect with one another. We are encouraging all women facing breast cancer, including Sharsheret volunteers and supporters, to post their personal stories on the blog and to provide inspiration to others. Sharsheret's blog also features postings by staff members as well as pictures from conferences and events and informational videos. We hope this teleconference will inspire all of

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you to participate in Sharsheret's blog, connecting women ala the 21st Century.

It is now my pleasure to introduce our first speaker. Linda Blachman is a personal historian, writer, and life coach specializing in the health of women's families and communities for the past 25 years. Linda has worked with cancer patients since 1995, when she became founder and executive director of the award winning *Mothers' Living Stories Project* (MLS), helping mothers with cancer to audio record or write life stories for their children. She created the MLS Training Manual and Educational Video. Linda also authored, *Another Morning, Voices of Truth and Hope for Mothers with Cancer*. I personally have had the pleasure of viewing snippets of a video highlighting a mom living with breast cancer as she shares her life story, and it was truly a stirring piece of work thanks to Linda's project.

So Linda I now turn the conference over to you.

II. Living Stories: Writing or Recording Your Life Stories.

Linda Blachman, MPH, MA

Linda Blachman: Thank you Shera. Good evening to everyone. I want to thank Shera for those kind words, Sharsheret for giving me the opportunity to share my work, and everyone out there for listening.

I'm going to be talking about different ways to think about writing and recording your life stories, whether as a healing process for yourself, a way to catalyze life's planning, or as a legacy for the future. I want to start by giving you what may be a new way to think about the stories of your life and by sharing some of my guiding beliefs as a personal historian and writer who has helped many people, including many women with cancer, record their stories.

First of all, I really believe that we all live through story. Barbara Meyerhoff, a well-known Jewish anthropologist, wrote in her classic book, *Number Our Days*, that human beings should really be called the story telling animal because we have a fundamental need to narrate our lives that's as basic as the need for food, clothing or shelter. I never forgot the first sentence of the Joan Didion essay that she wrote in 1970's, "We tell ourselves stories in order to live." And we do. From the time we're children, we begin to pull together fragments of our perceptions, parental messages, family stories, religious and cultural beliefs, and weave them together with our experiences and imaginings

into provisional answers to our questions about life. That's really what the stories are.

A story's not just this happened, and this happened, and then this happened, but it's what we tell ourselves about what happened and is happening. Another way to say it, is that stories are conceptual containers or perspectives, if you will, that make us feel secure by taming chaos into meaningful patterns. In this way, they fulfill two of our deepest human needs for meaning and for connection. Connection to ourselves or to others, to the past, the present, and the future, to the mystery. Stories tie us to the past and give us a sense of safety and stability, and they propel us forward by allowing us to imagine our futures. Just as all life is change; our stories too, unravel and evolve over time. They're really works in progress.

We tend to live in relatively stable periods or structures that we can call chapters that are punctuated by transitions. There are two kinds of transitions. The kind we choose, or that we author, like deciding to get married or to leave a marriage or a job, and the transitions where we're written upon and sometimes, we feel victimized by them. We're laid off, there's a natural disaster, there's a diagnosis of cancer. Any kind of transition opens up the big questions of life and then the task becomes, to reflect on what has happened; to revive our narrative in accordance with the new reality that we're living. If you're a parent, the task is also simultaneously to revive the narrative for your children. There are many pendants who say the biggest task of modern life may be managing uncertainty and transitions. While challenging, each transition can be an opportunity to see if we're living in accordance with our truest self and our deepest values. I believe that reflecting on

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your life and writing your story, your legacy; can help with these tasks of managing transitions.

When I founded the *Mothers' Living Stories* project, I trained volunteer listeners in deep listening and oral history methods to assist the young moms to record their stories for themselves and for their children. I also facilitated writing groups and began working privately with parents and non-parents of all stages of life and states of health, because I think this is a valuable thing to do at any time in your life. The mothers with cancer obviously had many needs, and I've often been asked, "Why did I make story rather than something else central to the mother's project?" That brings me to my second guiding belief for this work, which is that each of us has a unique and important story that's worth knowing and telling, worth revising and recording. I believe in the healing power of story. Isaac Dennison is attributed with having said, "All suffering is bearable if it can be seen and understood as part of a story."

I think most of us are probably familiar with the fact that telling our stories and having them received is at the center of support groups and psychotherapy in 12 step programs. There's a body of research started by James Pennebaker, a psychologist, that shows that writing stories through trauma or challenging transitions and writing with your emotions, has salutary effects on the immune system. There's another body of research and clinical evidence showing that reminiscence and life review have therapeutic affects, alleviate depression, and also help clarify values. In all of my work, the healing process of life review for the narrator is as important as the gift of legacy for those who will receive it the future.

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There are a lot of different kinds of benefits and ways healing happens, but I want to point out some that I found specific to people living with cancer. When you tell or write your story, you're really listening to yourself and that process helps you to reconnect with yourself. It's also a way to celebrate the life that you have lived and you can similarly re-find your voice. I know that with illness or trauma of any sort, we have a tendency to constrict the voice. Illness also tends to take over one's life, at least for a while. There was one young mother I worked with who said, "You know, I feel like I've become cancer. I'm nothing else." But after she reviewed her life and told her whole story, she felt her life had expanded again, that she regained perspective and remembered who she was and her larger life.

Telling or recording your story also has the possibility of helping you integrate the narrative of whatever you've lived through, any loss or challenge or your experience with cancer, into your larger life story. It kind of happens unconsciously that there's a tendency for story repair. It's also empowering to do something proactive for yourself or for others, even when your sickness has left you feeling that there's little that you can do. Whether it's giving this to your children or contributing wisdom to people you love or for a legacy for the community. You've become an author again, which in itself is also important and empowering. You also have the tendency after recording a story or reviewing your life, to see where you need to go next. Life review can be a launching pad or a path back to your life or into the future. Having your story received, whether with all its emotional content, whether by someone capable of holding it who's listening or someone who's reading it, is a powerful form of care.

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So far, I've been talking about life stories for insight, healing, and story revision, for yourself as your therapeutic process. It might be writing for healing or wellness in a writing group, writing for a blog, writing privately in a journal or even writing a more serious autobiography or it could just be telling your story to a friend or to a counselor or a personal historian who can guide you through the process. Now, I'd like to segue into an overview of the types of forms of stories and legacies, which brings me to a third guiding belief. Each of us has a story that is worth passing on and there's that word legacy, which comes from the French word, le'guer, or what we leave behind. I don't think the idea of legacy should be reserved only for the elderly or those facing critical illness. Every day of our lives, we're creating our legacies and making memories, whether in our choices or actions or by projects we do; by scrap-booking or putting together a photo album, things that we enjoy doing and can be shared during our lifetime and also become handed down and left for others.

There are two major types of legacies. There are legal legacies, such as a will for our material possessions. We're only going to focus on the non-legal possessions, both intangible and tangible, that can become legacies. There are three different kinds I'd like to distinguish. The first, many of you may be familiar with, is genealogy, the facts, dates, places, and names, which become family trees or family medical and genetic trees. I like to think of genealogy as the skeleton of a life. Then there's what we've been talking about, personal and family oral histories, which I think of as the muscles or organs, which can be for healing and for therapeutic purpose or intentionally recorded for others.

Here's where you tell or write what happened with all the detail and scenes and characters.

In terms of the media, you can tape an audio book or you can do a video documentary, you can write a book, whether a full autobiography or memoir, and again, journals and diaries that can also be left for others, even though you may not start that way. You can engage in story core and tell a brief but meaningful story that's given to someone you care about and then archived in Washington, D.C. Thirdly, you can prepare a life letter, which is a legacy letter. In the Jewish tradition, I think many of us are now familiar with the idea of ethical will. I often use the term life letter because ethical will is such a misnomer, it's not a legal will and it's not only about ethics. I think of the ethical will, not as a skeleton or the muscles or organs, but really as the heart or the guts of a life. When you're preparing an ethical will, whether by video or audio or more traditionally by writing it, you're going underneath the stories and beneath them to see how you can make sense of all the stories of your life, what meaning you ascribe to it.

On Yom Kippur, we do an accounting of our soul, that's really the heart of doing an ethical will. You're evaluating your life and passing on what you've learned; your wisdom, your values, your regrets, your spiritual beliefs, appreciation of teachers, mentors, messages of forgiveness and gratitude, wishes and blessings. Again, with the ethical will or life letter, you can audio record, video tape or more traditionally, write. It can be done as a free standing document or practice or it can become a chapter in your larger life story or woven throughout your story. In the *Mothers' Living Stories* project, I've done it in all ways. We did a full life review, an illness narrative and ethical

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will, and then a special tape with messages for children. Other legacies are photo journals or scrapbooks, recipes, quilts, your own music, but whatever you do and whatever form you use, there are great benefits to those who will receive it in the future.

When to do this? It can really be done at any time. Recording a story is often done at periods of life transitions. For people who are going through illness, I have found that it's often very effective to do just after chemotherapy or radiation, when you're suddenly done with all of the crises of medical treatment, although it can be done throughout treatment as well. It's often a good time to reflect. Life letters or ethical wills are often done as gifts at life cycle events, like a Bar Mitzvah or a birth or a major birthday. They can be given now to communicate about values in the family or between a couple. Some are written as gratitude letters during the holidays. Whatever you do, I really urge you to choose something that is right for you, that's enjoyable, that's meaningful for you to do. Don't make a monster out of the project, start small and find support for doing it.

In closing, when you review your life and record your story, your life letter, you explore key questions that are really never too early in your life or too late in your life to ask. How have I lived so far? What have I given to life so far? What have I learned? Those questions naturally lead to others that can help you live more fully in the present, which is really what it's all about. How do I want to live? What do I still want to give to life? What do I need to learn? What do I want to leave behind? In Jewish terms, how do I make my story sacred in whatever time I'm given in life? These are questions worth asking for any of us at any time.

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Thank you so much.

Shera Dubitsky: Linda, thank you. That was beautiful and I believe that you gave us a meaningful way to contemplate documenting our life stories.

I would like to now introduce Janet Falon. Janet is an award-winning writer and writing teacher. Author of the *Jewish Journaling Book*, her work has appeared in the New York Times, Philadelphia Inquirer, and other periodicals and anthologies. Janet teaches writing at the University of Pennsylvania and at many corporations and hospitals. She has been teaching journaling workshops for 25 years and we are honored that she is sharing her expertise with us this evening. Janet, the floor is now yours.

III. Journaling Through Breast Cancer: A Means of Self-Awareness and Self-Expression

Janet Ruth Falon, MLA

Janet Falon: Thank you very much. I really appreciate the opportunity to be speaking with everybody. It was a real pleasure to be listening to Linda, because so many of the things she said really resonate with the kind of work that I do, too.

I find it really confirming that a lot of the things I think work for journaling, work for blogging, and work for life story. I think it's all the power of expressive writing and how that is very, very healing. What I want to do while I'm speaking with you all, is to debunk some of the myths of journaling, which I think might prevent some people from keeping a journal that is as vital as it can be. I also would like to give

specific examples of exercises. You might, if any of the exercises sound interesting to you, write them down and do them soon.

I should mention that I've been keeping a journal for 45 years. I started very young and happily, I've not had breast cancer, but I have used the journal to get me through all sorts of difficulties; medical, spiritual, psychological. The journal, for me, has been the wonderfully accepting space where I can write just about anything. Like many people, I often find that I learn what I know by writing it down.

In terms of journaling itself, I want to say up front that a journal can be used interchangeably with the word diary. I've created my sense of what a journal is, my definition, and I just wanted to tell this to you all, because I think you'll see in the definition how the sense of journaling really can be expanded. For me, the journal is a record of personal experiences, observations, thoughts, ideas, and reflections, that is largely verbal, but can also include graphic expression and tangible mementos. In most cases, the journal is for private use.

This is one of the issues that you'll be hearing us talk about tonight: whether you're writing for your own self, which is great, or whether you're writing it to share with other people. I think all of the speakers would probably agree that most people, if they're writing for others, might write things differently than if they're just writing for themselves. Not necessarily better or worse, but I think it's really important when you do this kind of writing for healing, to have a sense of who your audience is. If it is just you, that's great and that is enough. If you decide you want to share the writing with other people, that's great too. Both are useful, both are definitely useful.

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Linda mentioned James Pennebaker, who's really been a wonderful leader in this field of expressive writing. He has said over and over and brought all kinds of examples, that expressive writing is helpful, physically, mentally, and spiritually. In fact, in one of his books he says, "Studies now suggest that women who don't express their feelings of their major traumas or stresses are at greater risk for early death due to breast cancer." In one study for example, women who did not openly express negative emotions, such as anxiety or anger were more likely to die within the first year of treatment than more expressive women. I'm not saying this to scare anybody, but I think it's just really a dramatic indication of how much expressive writing really can be so useful for your souls.

There are many, many reasons to keep a journal. One of the things to also keep in mind is that for some people, when they're dealing with a major stress like breast cancer, people need a place to go where they can be totally self-aware and self-centered. That's one of the great things about a journal - this is where you can write down everything you're feeling, everything you're worrying about, and you don't have to worry that anyone else is going to look at it and judge it. What's also really interesting about a journal is that some people when they're dealing with a stress like breast cancer, are sort of sick of themselves or sort of sick of all the things they're thinking. In a journal, they can focus on other people, which is actually very interesting. You will probably know yourselves whether you need the journal to focus on yourself or whether it's to get away from yourself.

Also, journaling can be fun. It's a place to be creative, it forces you to take time for yourself, and it helps you focus. As I said before, many people find that they know what they feel when they write it down, and certainly that's been true for me.

I do want to mention just a little bit about the Jewish dimension of journaling. There are four pieces of it, that when I was writing my book about Jewish journaling, were very interesting to find out. For one, there's a historic precedent to journal-keeping. Ahasuerus for instance, kept journals and in those journals they wrote down about how they achieved their alter state and what they experience in it. Another really interesting Jewish dimension to journaling is holocaust journals, which of course, are very good tools especially for people, like the historic revisionists, who think that the holocaust didn't happen. Some of these journals actually have been proven to be authentic.

There's sort of a spiritual precedence to journaling. It's the place where they are getting very introspective and the journal is a very introspective tool.

As I was thinking about all my years of journaling and how my Jewish sense came into it, I discovered that certain journaling how to's felt sort of Jewish to me. A simple example I recommend for people who are journaling, is that they should have a list of prompts ready. If they sit down and write their journal, they don't have anything they must talk about right then and there. They can look at the prompts and say, "Okay, this interested me at one point. I think I'll write about that now." That sense of readiness, that sense of being able to take the first step, reminded me of my favorite Passover person, Nachshon, the person

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who took the first step in the sea. This journaling list gives you that feeling of readiness, that you can do anything, like jump into the sea, when you need to do it.

Journaling can also be used, and I certainly have used this, to support spiritual growth and to stay engaged with Jewish things. The exercises can have an overtly Jewish slant if you like, or not.

What I'd like to do is to talk about some of the things that keep people from doing journaling as fully as they might. There are about six or seven of these things I wanted to discuss. The first would be that you don't have to write the journal every day. Many people think that they have to write every day or it's not a real journal. What often happens is that somebody will start a new journal and write for three or four days. Then they skip it for a day and then go back and write for four or five days, and then skip it for two days. Then they feel that they can't go back and write the journal, because they've already failed in journaling because they haven't done it every day.

What I would like to tell you right now, is that there's no cosmic rule about how frequently to write. You can write whenever you want to. Some people I know keep journals once a year or once a month. Sometimes when people write in the midst of stress, they might be writing several times a day. Whatever works for you is fine. There's no rule about how frequently to do it.

The second of these rules that I'd like to debunk has to do with moods. People will often go to a journal when they're miserable. They'll dump their feelings in there and it's very cathartic. But, if you only write the

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journal when things are difficult, then it's not really fair. It's not going to give you a fair depiction of what your life is like and I think it's important to validate all emotional states. Write the journal when things are terrific, write the journal when things are sort of ho-hum.

For me, writing is an act of committing - committing your time and your energy to this one task at that moment, when you could be doing many other things. In my way of thinking, if you only commit to yourself when things are difficult, the message to yourself is, I don't matter as much when things aren't terrible. I think it's really important to write the journal in all states. If you're writing the journal when you've had chemo and you're feeling terrible, it's great for that, but write it when you have a moment or a break where things feel okay - when you get a nice letter from somebody or when somebody calls you. Going back to James Pennebaker, who says, "Other studies indicate that women who openly express joy as well as negative moods have a longer survival time than those that don't express any emotion." I think that's very compelling.

In terms of debunking, the journal does not have to be only words and it doesn't have to be only your words. One of the things you can do, and I find this really liberating myself and I encourage you to try it, is to cut out other things and put them in the journal. In my journal, for instance, I have some of the fortunes from Chinese fortune cookies. In my journal, I have some advertisements that spoke to me. In my journal I have, believe it or not, the front of a candy box. I'm not going to tell you why that's there, but it was important.

That's what I'm trying to say, you can think of the modern journal as being almost like a scrapbook. Not the beautiful scrap-booking that goes on right now and which is lovely, but this is really where you're putting mementos, things that speak to you, into your book. Then what you can do, is respond to them. Let's say you put a letter that you got from someone into your journal. You can put it in the journal and that would be enough. Or if you want to, you can respond to it and say why you put it in your journal is.

What's also really interesting is that some people keep journals and they don't really think of it as a journal. The best example I can give you is my father, who was not an introspective man, died in 2000 and he never would have kept a journal. It would have been totally not him. When he died, my mother and I found a book of Haiku that he'd been writing, these little tight poems just 17 syllables, about getting older, about being Jewish, and about traveling. As far as I'm concerned, this was his scrapbook, because he was expressing himself there.

Another thing I wanted to say about with journaling is please think twice before throwing out a journal. Some people feel at the end of certain periods in their lives: I'm done with that. I want to move on. I'm going to throw out the journal. To be fair, I know of several people who've done this, for instance, when they went through a nasty divorce. They're done with it, they throw out their journal or burn it, and they're happy about it. What I want to say is that most people I know who do throw out an entire journal or a particular entry, regret it. If you're keeping a journal and you have moments of thinking, this is just horrible, I want to get rid of it, just wait five minutes or wait until the next day, because you may feel differently. If you think about and you

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say to yourself, this is really healing for me to get rid of it, then do it. I'm just suggesting wait a little bit before you throw something out.

If you're writing a journal and it's primarily about your dealing with cancer, you may feel when you get a clean bill of health, I want to get rid of that. Just keep it for a little bit and think before you get rid of it. I'm imagining that for most people, there will be things in their journal that will be useful for you to read and think about and share with other people later on.

Another thing is that the journal is about content. Your journal is not the place to worry about being a good writer. I love good writing, but the journal is about content. Don't worry about grammar and don't worry about spelling, as long as you can understand what you wrote. You don't have to be a good writer. Some people will take journal entries and make them more public, but that's not what we're talking about. The journal, as far as I'm concerned, is the place to dump, get the thoughts and the feelings out, and work things through.

Now, I want to talk about logistics. For instance, some people now keep computer journals. My feeling is if the computer helps you write more easily, more regularly, go for it. What I would do if I was keeping this on a computer, and I never have, is I'd write something in the computer, print it out, and then put it in my journal. I would glue it in and then I might respond to its words, or I might draw on it to make it pretty. Computers are great; whatever makes you express yourself is fine.

Some people have special pens that they only use for journaling. You don't want to write bills with that same pen, but there are some ritual things you can do to give this some sense of specialness. In terms of books and papers, I think a lot of us who are in this business loved school supplies when we were kids. And the book matters. I hate to be silly about it, but the book matters. The right size matters, whether it's lined or not lined. I never use beautiful books when I write my journals, because I don't want to write everything beautiful all the time. I want to be able to get nasty and mean and write terrible things in my journal and I don't want to do that in a beautiful book.

This is just the kind of thing that you learn as you do the journaling, what works for you. I would suggest that you carry paper with you all the time, because you never know where you're going to be inspired. A lot of people find that happens when they're on buses or all kinds of situations. Carry paper with you, it really, really matters.

Another thing about the paper and how to organize the journal is that after you write a particular entry, go back and look at it again and give it a title. That way, when you can go back and read your journal and you only want to read about certain things with let's say your sister, you won't read the entries that have to do with food.

Having the title on the entry is a really good way of going back to reread things if you want to. Some people reread journals, some people never do. Either one is okay. Some people find that when they go back and reread their journal, they say, oh my goodness, I still do that, or gee, no I don't do that any longer. Rereading is fine, but it's not essential.

I'm going to give you some specific exercises. Many of these have a Jewish component if you want, have a health related component if you want, or don't have to be at all. As I said before, the journal is the place to focus on yourself, if you want to, or to get away from yourself if you want to.

Number one, lists are great because they're short. You don't have to write them beautifully. You can write a really important, useful entry in five minutes. One kind of list you might want to try is a list of dependable joys; what can you count on in your life now, even if you're dealing with illness, that makes you happy? It's not to go from depression to euphoria, but what can you count on in the course of your day? For instance, petting your cat or eating your favorite breakfast cereal. After you've written the list, if you're having a tough day, you go back and say, gee I haven't pet the cat today and you go back and do it. This stuff can be extremely, extremely powerful and extremely practical.

Another suggestion would be a list of things you currently believe in and a list of things you no longer believe in. It can be very, very interesting. In terms of cancer and journaling, some people have given me wonderful list suggestions. One list would be a list of people who you want to let go right now in your life, who are not serving you well as you're dealing with illness. Another list would be a list of uplifting people to be around as you're dealing with your illness. Another interesting one is what you've learned from cancer. The last one I'd like to suggest is a list of the ten things you don't want to tell yourself right now, things that you're sick of hearing, and things that don't work

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for you. There are many, many lists. Lists are great and if you wrote your whole journal in lists, you'd be fine.

Another thing you can do is write the altered point of view, which is to write the journal as if you were someone or something else. For instance, you might write the journal as if you are chemo or you can write the journal as if you are a breast. You can take that to another level and dialogue. Let's say you've written a journal as if you are your breast. You can have the other breast write back to it or you can talk to it. I know it will sound goofy, but you'll find that these kinds of exercises really allow some very important stuff to come up.

Dialoguing is something else to try as well. The final thing, which I'm sure the other speakers have dealt with at one point or another, is called unsent letters. These are letters that you write that you of course, never are going to send. For instance, you can write a letter to yourself now from yourself on the day when you're cancer-free.

In closing, I want to say that journaling is a fabulous tool. It's malleable; you can take it and make it your own. I hope it will be something that you will use and that will help you get through this difficult period well. Thank you so much for listening.

Shera Dubitsky: Janet, thank you. I'm not currently journaling, but I love those lists that you suggested. I also believe that you gave us such useful and thoughtful guidance as to how to proceed with journaling our experiences. Thank you.

Our last speaker tonight is Jill Cohen and she is a Sharsheret Caller who became a Sharsheret Link. Jill started her blog, Dancing with Cancer, shortly after she was diagnosed with metastatic disease at the age of 42. Since her diagnosis, Jill has focused her activism on behalf of women living with metastatic disease. Her blog was rated excellent and it came in third out of 75 breast cancer blogs reviewed by editors.blogs.com. We are truly grateful that Jill has agreed to share her blogging experience with us this evening.

Jill, the proverbial floor is now yours.

IV. Why Do I Blog? Education, Convenience, and Tired of Repetition Jill Cohen, Blogger

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Jill Cohen: I want to thank Sharsheret for including me in this teleconference. I am the novice here. I don't have any professional credentials as a writer and blogging is the first writing I've done for the public outside of my experience in the workplace.

Let me tell you briefly a little bit about me. My name is Jill Cohen and I have basically been living with breast cancer for 10 years. I was 39 when I was originally diagnosed at Stage II. I had the gold standard treatment at the time: lumpectomy, CMF (chemotherapy regimen), radiation. But a few years later, my cancer returned and it had spread extensively with metastases to more than 20 bones in my skull, sternum, spine, humerii (those are the upper arms), and femurs (the long bones in your thighs).

A few months ago, I was also diagnosed with three new primary tumors in both breasts. All of my cancer has been ER/PR positive, so the meds have responded really well to anti-estrogen drugs and I've been more or less stable until quite recently.

I have written an ethical will, which Linda spoke about; I've done journaling, and what I learned from all of that when I was in active treatment is that I liked writing. I never really thought of myself as a writer before. It was hard to get started, but once I did, with a kitchen timer set for every 15 minutes, I found that I really love it. Even though I don't have published credentials, this is my effort not only at expressing myself, but also at linking up the world.

Why do I blog? I got tired of having the same conversation with different people every time I had news to share. When I was first diagnosed with breast cancer in 1999, my husband and I stayed in touch with family and friends via telephone and e-mail throughout the months of my treatments. Then I got better. A few years later, my husband had to have open heart surgery. We went back to the same thing - phone calls and e-mails. Then in 2002, when my mets were diagnosed, we started the mass e-mails again. We were sending e-mails to maybe a hundred people and it quickly became time-consuming and energy-draining.

E-mail software doesn't really permit you to send a hundred or more people a note, so you have to learn how to segment your e-mail addresses. You have to copy and paste and send things multiple times. We would get back all these replies from people, which was delightful, but it was also a deluge of e-mail.

After a year or more of sending these weekly or every so often e-mails, I decided that I would start a blog. The reason behind that was for my friends and family to read what I have to say at any time they choose, not just when I put it out there. They can click on my blog once a day, twice a day, once a week, once a month, whatever works for them. Most people seem to check in with me every couple of days, which is kind of nice. It does make me feel a little bit of pressure to write daily, but I have found that I have a lot to say. It hasn't been hard to keep up with a kind of self-imposed daily schedule, unless my lymphedema flares up as it has been lately, and then I have trouble typing.

By blogging, I can write a short note or I can write a long post about whatever part of living with cancer is on my mind for the day. Sometimes there could be several different things on my mind. I can rant about my frustrations with the managed care system. I can bemoan my frustrations with lymphedema. I can talk about how I manage pain. I can disclose new symptoms, new tumors in this case. I can talk about how I deal with new drugs and what their side effects are. I actually find that getting the cancer stuff off my chest, so to speak, every day helps me live the rest of my life without dwelling on cancer. I have this one little timeframe where I give cancer free rein. I get into it in whatever way I feel like doing that day, and then I can actually go on to live the rest of my life without being stuck in cancer land.

For me, the best part about blogging is that I don't have to repeat myself several times a day every day to different people. In addition to blogging about cancer, I blog about holiday celebrations, cooking, what it means to be Jewish, gardening, and my dogs. I also blog about spiritual matters - what it's like to live with cancer, what it's like to grieve friends who've died, what it's like to think about your own death from cancer. Believe me, these are issues you think about when you have metastatic disease.

I find that when I do have important news to share, such as test results, I'm still getting on the telephone with my immediate family to tell everyone what's going on. In that way, I'm still repeating these conversations because I'm telling them the same thing time after time, but I want to make sure that they understand clearly what's going on. But for the rest of the world outside of that circle of immediate family,

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it's much easier for me and for everybody else for people to check at their own convenience, rather than waiting for me to be in touch with them.

Now I've got to warn you, not all of my friends read my blog. Some of my closest friends do not read my blog. I get a little frustrated with them when they say, what's going on? And I say, "Well, have you read the blog?" Then they say, "No, I don't do that." Occasionally I'm still in the position of repeating information, but because those are the people who are closest to me in my inner circle, I'm willing to make an exception for them.

There's one unexpected benefit about blogging, aside from being a great way to stay in touch with friends and family. It turns out that blogging gives me an opportunity to educate members of the public who find my blog about what it's like to live with metastatic cancer. Metastatic cancer of any kind, much less breast cancer, doesn't get a lot of mention in the press. I think I also feel a need to provide information for people, whether it's a woman who's just been diagnosed, someone who has a family or friend in their circle with metastatic cancer, or someone who is just surfing the internet.

Somehow, I'm always surprised that people find me. There's an opportunity for folks to leave comments on my blog and most of the time, I enjoy the comments that I get from people I've never met. Occasionally, I receive comments that I don't welcome and I'm able to delete those comments so that no one else has to see them.

My blog is called Dancing With Cancer: Living with Mets, a “New Normal.” I was rated independently, to my great surprise, by a Web site called Blog.com where real people review blogs. They rated me a 9.4 out of 10 points. I just double checked today to see I’m still up there and now I’m number two out of all blogs on metastatic cancer.

That was surprising, but I was proud to receive that kind of recognition. As I say, I’m not a professional writer; I’m just a person putting my story out there.

Why did I call my blog Dancing With Cancer? I’ve been a dancer all my life and the image of sometimes leading and sometimes following really spoke to me. When you do partner dancing, one person is leading and one person following. In my life, sometimes cancer is leading the dance and I’m following it. But there are times that I’m in the lead. I have to say I didn’t learn quite enough about how to blog before I started blogging, so the name of my blog, Dancing With Cancer, is not the same as the URL. It turned out to be a little too much trouble to change that after the fact. If you want to look me up, you can Google “Dancing With Cancer” or you can just type into the bar of your Web browser, www.jillscancerjourney.blogspot.com.

Shera Dubitsky: Thank you Jill. I suspect that your discussion really resonated with many of the women participating this evening and I appreciate you sharing.

V. Question and Answer Session

Moderated by Shera Dubitsky, MEd, MA

I'd like to now open the floor for a brief question and answer period. I ask that you keep your questions general and broad enough so that all participants can benefit from the discussion.

I'd like to begin with several questions we received through e-mail and the first question is for you, Linda. The woman writes, "I feel conflicted. On the one hand I want to write my life story for my children, but I worry that sometimes this can be an emotional process. Do you have any suggestions dealing with this and do I withhold information that might be too overwhelming for them?"

Linda Blachman: Well, thank you for those questions. These are the kinds of questions most of the women I've worked with are handling. It is an emotional process. I think it's difficult for it not to be. One way to think about it is to make sure that you have some support for doing this. You could do it in a writing group or with a friend or buddy. Some of the people I've worked with are cancer patients who when they're really going through a rough time and they're doing this, they know it opens up a lot of emotions and they usually schedule a therapy

appointment right afterwards. Though you don't have to necessarily do that, but make sure that if there are issues that come up during the process, you have a safe place and a safe person who you trust to be able to talk about and deal with some of the issues.

With regard to the question of withholding information, that's something we've struggled with. People struggle with it at different points and in different ways. To record your story, whether it's writing or telling, for it to be as valuable and healing for you, you're going to want to express as much as possible. You don't want to censor yourself too much. The wonderful thing about editing is that you don't have to censor yourself. It depends on how you're doing it. If you're doing it into a tape recorder, it can be quite expensive to edit audio tapes or video tapes. If you want to do it yourself, you can write things out first and then edit later. As a writer myself, there's no way that I could write a first draft and then leave it for someone else to edit.

When I record life stories with people, say with audio tapes, I just judiciously use the pause button or give control to the person who's telling the story. This way, they can press the pause button to talk about things that are coming up that they don't necessarily want on the tape.

There's another issue about withholding information that has to do with privacy. I try to help people before they start the process to really think through what they're going to say, if they know that this is going to be for their children. What are the risks and benefits of sharing particular pieces of information? How will I be benefited? How will the children

or recipients be benefited? What are the risks to me in telling? What are the risks potentially to other people?

It helps if you have someone else - a friend, mentor, counselor, or someone in your life who you can think through those issues with. It's important in terms of what is going to be left behind and words can be quite powerful.

Again, writing drafts, thinking about it carefully, editing in whatever way you need to later, are all important. One other thing we did in the Mother's Project, when we realized that this could be a big issue, was we would have mothers make a separate tape that was age appropriate for their children. This was a kind of emotional insurance in case something happened depending upon the level of illness. They might be recording a story or a favorite poem, so the children would hear their voice and talk about things in age appropriate ways. They saved the remainder of the story for a more appropriate age, like when the children might be adults.

Shera Dubitsky: Thank you so much Linda. The next question we received is for Jill. The question is, "I have been updating my experience on a website called Care Pages to avoid repetition and to control the flow of information. I'm having a hard time setting limits with my friends and family. They think that since I am being open with them, it gives them permission to offer unsolicited advice. Do you have any suggestions?"

Jill Cohen: I have a friend who blogs regularly. When she puts up her post, she adds in big red capital letters, DO NOT GIVE ME ADVICE. It's very important I think to set boundaries with people. Care Pages is a great

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tool for this kind of thing, but you may have to have a disclaimer every time you post something significant. It can be something like, "Please don't give me advice. I trust my doctors and I believe I'm making the right decisions for me." You could also be even blunter and just tell people to respect your limits but to butt out. I don't think it's inappropriate to tell people to please respect your decisions because you know that you're doing what's best for you.

Sometimes when people give me unsolicited input or gifts, I yes them. I say, "Oh thank you. That's very sweet." After ten years of cancer, I have this big box of stuff that I had never cracked open and I gave it all away. Now I say to people, if it's a suggestion related to healthcare, "I'll consider bringing that up with my doctor."

Shera Dubitsky: Thank you, Jill. Janet a question came in that maybe you can address on the heels of what you were talking about in terms of the journal not being strictly written. The question was, "What are your thoughts about having somebody else write in your journal?"

Janet Falon: I guess the most important thing is to figure out up front is how you want the journal to be. Let's say, a friend writes a letter to the person in the person's journal and this friend is very caring and really wants to express friendship. Rather than write in the journal itself, the person might want to write a letter or e-mail that can be printed out and put into the journal instead of writing in the journal itself. Most people that I've known like to write in the journal themselves, they don't want anyone else's handwriting there. It's really theirs and they want the choice to include other things in the journal or not.

I love the idea of someone wanting to contribute to the journal. I think that's great, but the journal-keeper needs to decide whether she wants the person's input directly or if she would rather use some things that they send to her. If the person sends something and you could put it in your journal, you get this sense of the journal being expanded. It's not just writing about yourself, which is fine of course, but you also have other people loving you and caring about you in the journal and I think that would be great. But I think the person who's keeping the journal needs to decide what she wants.

Shera Dubitsky: As I saw this question come in, I was wondering if maybe it's the antiquated version of the blog. This way people can comment on what you've written, which is great for people who may not be computer savvy.

Janet Falon: Yes, if someone writes an e-mail to you and then you can print it out and put it in the journal, the person is contributing to it. Blogging is really wonderful too, because of the immediacy of it. You can really do things quickly whereas with a journal, it might take a longer time.

Shera Dubitsky: A question came in about using Twitter instead of the blog. Jill, what are your thoughts about using Twitter versus the blog? Also, if you can briefly describe what Twitter is.

Jill Cohen: I'm not so familiar with Twitter, but I think it's a bit like Facebook in that you really just post one sentence about yourself. It's a kind of snapshot, like what am I doing right now? But it doesn't have an opportunity for me to say more about what I'm doing and how it relates

to my life. I have an awful lot to say and Twitter just doesn't permit that.

Janet Falon: I wanted to say something about Twitter as well. One really important thing about journaling is that there are certain days when all you want to express is one big word with an explanation point. There are other days where you want to go on pages. If I were doing something electronic, I would want something that seemed more open-ended where I could write as much as I wanted to or less. That strikes me as being important.

Shera Dubitsky: Thank you. The next question that came in is, "I do something different - an unwritten monologue titled, Nightmare of Living Hell, in open coffee houses. How would you classify this?"

Linda Blachman: That's simply incredible. I would classify it as a non-written monologue. I don't think it matters what it's called or what the label is, I think what's important is that it's a form of self expression and that it's working for whoever the person is that's doing it. It's a form of art and self expression and to some extent, what it's about is finding your own way to tell your story and it might turn out to be a performance piece.

Shera Dubitsky: Our last question goes out to you, Jill. This is a logistics question, "How do you actually start a blog?"

Jill Cohen: I Googled blog and I found all these sites that allow you to host a free blog. I don't pay for my blog, I didn't buy my own URL, and I'm really doing this as a complete and total amateur. In my research, there are

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a number of different sites that give you the opportunity to host free blogs. For me, the best appeared to be Blogger.com and it seems to work pretty well. I don't know much HTML, which is code for how you write in a website. This has pre-arranged type faces and items on a page and it's very easy to use. I might be a bit savvier than the average person, but for me it was not hard to learn how to do this.

I know people who have a blog that and they just post letters on it every day. I have more stuff, like links, pictures, and a free counter that displays the number of people who have looked at my blog. I did these things by using a search tool and doing some research before I got started.

VI. Teleconference Conclusion

Closing Remarks

Shera Dubitsky: As we wrap up this evening, I'd like to thank all the speakers for so generously sharing their wisdom, experiences, and time. All participants are invited to visit the websites of all our speakers who presented this evening. I also encourage you to reach out to Sharsheret anytime for support and resources. Sharsheret's phone number is (866) 474-2774 or you can email me directly at sdubitsky@sharsheret.org.

I invite you to share your stories. All of you, as the speakers said, have a distinct experience, a unique perspective that might just touch the lives of other women living with breast cancer. By hearing your story, other women can feel less isolated. We have already received meaningful feedback from women who have read an inspiring piece in

Sharsheret's booklet, Our Voices. Some people have contacted Sharsheret because they read a news article or a human interest story about women who were supported by a Sharsheret Link, a peer supporter, or received our materials and resources that gave them the encouragement that they needed to get them through their breast cancer journey. Please contact our office to find out ways that you can get connected by sharing your stories in the Our Voices booklet or by pitching your story to your local news media.

Right now, I encourage all of you to visit the Sharsheret blog at sharsheret.blogspot.com, where you'll see a reference to tonight's teleconference. Please feel free to comment or share a story of your own by clicking on the comment box. We certainly look forward to reading what you have to share.

I want to thank all of you for joining us tonight as we explored the power of the written word.

Good night.

VII. Disclaimer

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