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Practical Tools for Living With a History of Breast Cancer

Anita C. Broxson, MSN, RN, OCN

February 28, 2009

JENNA GLAZER:

Good afternoon, everybody. Welcome to ... "Practical Tools for Living With a History of Breast Cancer." I am Jenna Glazer ... associate director of development for the Young Survival Coalition [<http://www.youngsurvival.org>], and a four-and-a-half year breast cancer survivor. I want to let everybody know that this workshop is being audio recorded, and it's going to be duplicated or made available for public use.

We're very lucky this afternoon to have a fantastic speaker with us — Anita Broxson. [She] is the program director of the Beth Sanders Moore Young Breast Cancer Survivors Program at the University of Texas M. D. Anderson Cancer Center in Houston ... [<http://www.mdanderson.org>]. Her research-interests include survivorship, identifying and addressing quality of life issues, and meeting the educational needs of young women with ... breast cancer history. Ms. Broxson also served as an Anderson Ambassador since 1996. In that role, she educated the public and other healthcare professionals about a wide variety of cancer-related topics. Her affiliation with the Young Breast Cancer Survivors program has resulted in [speaking] invitations ... about the program locally, nationally and internationally.

... This workshop will be divided into two sections. We're going to have 20 minutes of lecture, followed by 15 minutes of discussion and questions. Everybody can just raise their hands and I'll bring the mic over to you. There will be another 20-minute [lecture], followed by another 15-minute question-and-answer session. I hope everybody enjoys [the presentation].

ANITA C. BROXSON, MSN, RN, OCN:

Thank you. I decided to break it up a little bit, because it is the end of the day and it helps you kind of stay awake. (Laughter) I'm a morning

person so, you know, I'm much sharper at this in the morning.

Throughout this presentation, I'm going to be inserting quotes from young breast cancer survivors who participated in [my] focus groups ... a couple of years ago. I found some quotes I thought were very pertinent to what we're going to be talking about today. One said, "When I finished chemo, my doctor said, 'Okay, you're done. Go back to your normal life.'" Well, [one survivor replied], "What? What do you mean, 'normal life?'" Another said, "I had no idea what to expect." And [still] another said, "There needs to be a guide to survivorship," [an opinion that became] ... the consensus [among] ... the focus groups that I did. How many [here] would agree with that? [That you feel you] need[ed] something [to] tell you what happens next, now that you've finished chemotherapy, or radiation or whatever [follow-up treatment] ... you're [enduring]. ...

So we're going to be talking about a survivorship plan-of-care. It's also called a survivorship care plan or treatment summary. [It is a process that is] known by many names. We're going to talk about what it is exactly, why ... you need one, [and] how you can create one. [Then we will] share some of your thoughts ... at the end of this first [lecture] session.

[After that], we'll talk about communication: because without communication, [the survivorship care-plan] is [not] going to happen. We'll talk about communicating with your healthcare providers about survivorship issues, as well as with your family, friends [and] employer. Then we'll do some more sharing time, [and answer] any questions you might have about communication or anything [else] that we talk about [this] ... evening.

These are words from a young woman who [is not a] ... breast cancer survivor, [but did survive non-Hodgkins lymphoma]. I thought her words were so pertinent I had to include them: She said,

"On day-one of my last chemo, I felt like a puppy about to be tossed out of the litter. It hadn't occurred to me that my routine journey from Planet Cancer would be almost as turbulent and twice as lonely as the first leg of the trek." You can see why I would have chosen a quote like that. In case you haven't heard of her, her name's Joni Rodgers [<http://www.jonirodgers.com>]. She wrote a book called *Bald in the Land of Big Hair* that caught my eye. The cover [shows the back of a woman's head. The woman is completely bald, with stark-white mannequins on either side of her, all with big-haired wigs on them] — the Texas big hair of the 80s. ... (Laughter) Remember Southfork? ... She's in the photo, but she's the one without any hair. She said it was very intimidating to move from Montana to Texas, where they had big hair and she had none. So she [incorporates] a lot of humor in [to] her book.

Another reason we really need to talk about survivorship-care plans is [due to the number of survivors out there]. There are ... more than 200,000 breast cancer survivors today, or young women with a history of breast cancer. When I say a history, I mean personal history: You, yourself, have had breast cancer. [Add to that] ... more than 23,000 [people under age 45] ... of you are friends or colleagues [of people who] will be diagnosed [with breast cancer] in 2008. It is [anticipated to result in more diagnoses than] ... any other type of cancer. We know more women die from lung cancer, but more women will get breast cancer.

So ... who actually is a survivor? Because that is a term that gets tossed around a lot, it has a lot of confusing definitions. The official one from the National Cancer Institute [<http://www.cancer.gov>] is that an individual is considered a cancer survivor from the time of diagnosis through the balance of ... life. Family members, friends and caregivers are also impacted by the survivorship experience — I think we'd all



agree with that — and are therefore included in the [survivor] definition [in other schools of thought].

However, the care-plan that I'm going to be speaking about does not target all survivors by that [broad] definition. Its focus is on ... extended survival, which is that transition from the end of active treatment to post-treatment. At the time you ended that active chemotherapy, radiation, surgery — whichever was your primary modality — [your extended-survival period began]. When ... you went into that time of either being on tamoxifen or something related to tamoxifen — or nothing — that beg[an] survivorship, [and that is when information for a] care-plan [becomes useful]. You'll see why as I move on.

This [notion of an extended survival period, and the need for support in that phase] gained a lot of attention a couple of years ago. [That was when] the Institute of Medicine did a report [<http://www.iom.edu/?ID=30869>] called *From Cancer Patient to Cancer Survivor: Lost in Transition* ... [The word "report" is kind of an understatement, because it's a book on survivorship [available through the National Academies Press http://www.nap.edu/catalog.php?record_id=11468]. It address[es] many of the deficits in cancer care that occur when people end active treatment. We need this plan because, as another young woman [once] said, "What happens if I move or I change doctors?" We know ... [we are living in] a mobile society. You may have finished a degree, moved on, taken a job — [made] a career move. You have many things that can cause you to change where you're being cared for. One [person] said, "Now that I'm a survivor, I didn't get any material." That's tragic. You need information just as much [after treatment] as you did when you started chemotherapy. As some of my ladies said, "We need a survivorship bible. Where is my bible?"

We know that having this plan will help us to promote continuity of care as [people with cancer] ... transition ... from one phase of care to another. [The information in the report] certainly enhances communication between you and your health care providers. Another young woman said, "I felt so abandoned, [thinking to myself], who's going to care for me now? Who do I call?" Have you all had questions like that? Yes. I'm sure [you have]. ... One [woman] said, "I feel like I'm back in that maze again." She described when she started chemotherapy ... that she was pulled in so many directions. She didn't know where to go. She didn't

know where to [get] ... information. Eventually she got that information [and] things settled down. But then ... she transitioned [into] the end of active treatment, [and] she felt like she was back at square-one again. ...

... So, the treatment summary, or what you may hear of as a patient-care plan, a survivorship-care plan, a plan-of-care or treatment-summary: Has anyone's oncologist or nurse practitioner or P[hysician's] A[ssistant] talked to [her] about creating a plan? If so, raise your hand. One? One, two? Okay. Well, I'm glad we're doing this.

You don't have to wait for them to talk to you. You can talk to them, and it's a good idea [to do that]. There are some key things you can ask them for. You can start a notebook. Many of you may have started notebooks when you [began] ... treatment. Think of it as the continuation of that — the next step. There are a couple of major things in there that you would want to have [recorded]. The first section I would call the essential treatment summary. [One section should include] ... contact information for every doctor who cared for you during your active treatment: your radiation oncologist, your medical [oncologist], your surgeon. I have them listed on that [handout I gave you]. I won't go through every single one. But just think of every doctor who had something to do with your cancer care. You're going to want [new doctors who care for you after your cancer treatment is complete] ... to know who those people are. [That way they can] ... contact them if they need to — if they have any questions.

You're going to want a list of dates of your surgeries, [the] type of surgery ... , whether [a surgery included] biopsies — anything that yielded a pathology report — [and copies of any] ... pathology reports. That pathology report is th[e] report that says exactly what type of breast cancer you had, ... whether you were ER [estrogen receptor] or PR [progesterone receptor] positive or HER2 positive or negative. That's important information to carry forward. Think of it as a chronological history of your life, [a history of your experience with] ... breast cancer.

Then you'll want to ... [record] what chemotherapy [medicine] you were on, particularly if you were on an anthracycline, [such as] Adriamycin, because it's a lifetime dose that you can have with [this family of medicines]. Although your doctor is going to keep you within that limit, heaven forbid ten, 15 years from now something else happens and you need another anthracycline.

[If that's the case], they need to know how much you had [in the past]. So you want your [history of] dosages [recorded]. If you had any ... unusual effects from those treatments, that needs to be listed [as do any] hormonal therapy [treatments with] dates [of use including] ... start- and stop-dates. For tamoxifen, if you went from tamoxifen [to] ... menopause, then went on an aromatase inhibitor — all those dates and [medicines] need to be recorded. [Also take note of] any other [targeted or newer] therapies you may have had ... [such as] ... Herceptin, [also known as] trastuzumab. ... Then your radiation history: the dosages, what they call the gray, the Gy, how many grays [units absorbed] of radiation you had, and the location, whether [the cancer] was your nodes, and whatever was radiated. So basically that treatment summary [is a detailed record] of what actively helped get rid of your breast cancer.

Then looking at long-term and late effects — you'll hear both of these terms interchangeably: But, technically, ... late effects are those that may occur anywhere from three ... to five months, to five years, or [even] ten years after your breast cancer [treatment]. For instance, lymphedema: you may not have had lymphedema at all [at the initial diagnosis]. But ten years later, it can pop up. Lymphedema can happen at any time.

Long-term [effects] will be something that started during therapy and continue[s] on. So, these are effects that [your healthcare providers] would need to watch ... So if you go to a new doctor, or you're not seeing your oncologist anymore but you're seeing a family nurse practitioner or a G[eneral] P[ractitioner], ... or your gynecologist, they need to [be alerted to any potential conditions] ... Because if you show up and they have no idea about your cancer history, and you start having ... delayed effects, they need to be able to connect that back to the breast cancer. Then they'll need to know about your hormonal therapies as well, because that [continues] for years after you have finished [treatment for the cancer].

Also, you'll need to ask your provider, "What are the signs that I need to be reporting to you? When do I call you?" ... Young women would [often] tell me ... "I had no idea when I was supposed to call. If I had a hangnail, I thought I was supposed to call. I was afraid it was cancer ... if I had a lump on my big toe, I thought it was cancer." I'm not laughing at that, but she would laugh at herself, and she'd say, "I know it's ridiculous. But I feel like I don't know when I'm



supposed to call the doctor." So ask [your doctor what your individual red-flags are and when you should call]. Make them take the time, and write down [what they say]. If you decide to go out to Web sites to look for this information, just make sure you're looking at good, reputable Web sites that end in ".org" or ".edu" ... [The Web sites with ".org" and ".edu" ... generated by academic medical centers or universities.

You will also want to ask [your doctors what to] ... watch for [in regards to] recurrence and when you're [supposed to] report those symptoms ... If you get a new ache and it goes away in a day or two, or you've done some new gardening or something, that's nothing to be concerned about. But if you have something that stays with you, that is persistent, you want to at least contact [your doctor's office] and talk ... about [your symptoms]. But [your breast cancer history and related conditions, symptoms, and treatments] are the things that will need to be listed in your [care]-plan [so your doctor has a frame-of-reference for your symptoms]. For instance, if there's a new lump, some bone tenderness, shortness of breath, a new pain that's not going away, certainly nipple discharge, or vaginal discharge or bleeding when on tamoxifen, [all of those situations would require a visit to your doctor].

Of course, you'll ... need to do your annual mammogram. There are guidelines for that [http://www.cancer.org/docroot/CRI/content/CRI_2_4_3X_Can_breast_cancer_be_found_early_5.asp] ... [Also remember to have] your annual pelvic exam. ... After breast cancer, there's still the rest of your body you need to pay close attention to. Genetic testing may or may not be recommended ... depend[ing] your particular situation. I'm sure you've heard a lot about that here in the conference, because I know I've seen breakout sessions for information on ... BRCA I and 2.

One thing I want to say about what is not recommended — because I know this gets asked a lot: "How come I'm not getting a CT [computerized tomography scan] every three months," or every six months or a PET [positron emission tomography] scan or tumor markers, some of the things that you got during active treatment. [The reason those tests aren't done that often after initial cancer treatment is] because there's been no evidence to show that it makes a difference, and they're very expensive tests. The American Society of Clinical

Oncology sets ... guidelines [for when to order those tests] based on the evidence-based research [Editor's Note: Read the current guidelines: <http://www.asco.org/ASCOv2/Practice+%26+Guidelines/Quality+Care/Practice+Guidelines/Clinical+Practice+Guidelines/Breast+Cancer/American+Society+of+Clinical+Oncology+2006+Update+of+the+Breast+Cancer+Follow-up+and+Management+Guideline+in+the+Adjuvant+Setting>].

Your insurance companies will look at these recommendations, at what ASCO [American Society of Clinical Oncology, <http://www.asco.org>], the experts, recommend. If you have a doctor ordering a PET scan and it's not truly warranted, then you may be hit with a bill of ... \$18,000 for a PET scan. There are reasons why they aren't offered. They haven't been shown to make any difference, and ... they're expensive. ... Tests are ordered [when] there are symptoms. I know that's not [very] comforting, but that's the way that it is.

So, [back to information about] creating your [survivorship] plan: You want to ask your provider if they have a formal document [that gives details on what your care plan should include]. They may have one that they haven't implemented yet. They may have something that you can use as a guideline. Have your list of questions ready. ... Request some time for completing the form. It might be some extra time. I know ... I'm partial to nurse-practitioners, but the nurse-practitioners will take time to educate you about the survivorship plan and ... fill out [the form] with you. If you can plan it ahead of time, you can say, "Next visit, when I come in, here are some questions I want to be able to get answered." I think if you ask ahead of time, and they can plan for it, then they will help you complete that plan. And, by all means, save it. Save it in a couple of places, on a flash pen or a CD. ... Keep a couple of copies. Even take one to give to your primary care doctor when you go. But you're going to have to be proactive in most cases.

I don't know if this is going to work [with this group] ... but this is a great site. ... <http://www.oncolink.org/oncolife>. [It's just the oncolink.org site], and just forward slash oncolife. This is out of the University of Pennsylvania. You can go to this Web site and ... fill in blanks. It's going to be rather generic. You're not going to be able to put your doses or anything. But you'll be able to put in the names of [medicines] you've had,

[and] if you've had radiation or anything like that. ... You can [view] it in Spanish or English. And ... [there is] ... a place where it asks questions. It might take about ten minutes to [answer all of the questions]. ... Then [there] will be a drop-down list ... where you put in your race, age, age at diagnosis [and] relationship-to-patient [status]. You might be filling it out for someone else, or a nurse might be filling it out for you, or it might just be you [filling out the form for your]self. ... When you get finished with [the form], it prints out a plan that [gives direction based on whether you] ... [took] tamoxifen, [including information on what you should] ... watch for. [Or it may give information on what to watch for] if you were on Herceptin ... [or an] anthracycline, if you had radiation, different things like that. It gives you those scenarios and tells you things that you should be looking for down the road as you are recovering.

After you have that plan, please make several copies. Put it on a CD, a DVD, a flash pen. When I was working on my master's thesis, I was so paranoid about it being lost. They told a story in school about somebody who had it saved one place, and there was a fire in his apartment, and he lost all of his research. [The advice with that story was] that the freezer was the best place to keep [a disc] — this was the floppy-disc [era]. ... I don't know what happens to the [newer storage devices if you put them in the freezer]. ... But this was a floppy. So, I put everything on a floppy, and I stuck it in my freezer, outside in the garage. My husband came in with it and said, "I know you're really losing it now." (Laughter) I said, "Why?" And he said, "Because look what I found in the freezer." I said, "I know." He said, "Why on earth would you do that?" I said, "It's safe." He really thought I was crazy.

... Anybody who's done a thesis or a dissertation [knows why I would do that]. ... It's a lot of work, and you don't want to lose it. [The same goes for the information in your survivorship plan] — you don't want to lose th[at either]. So [make] ... multiple copies, in case you walk off and forget one at home.

Make sure you can share [your plan] with your healthcare providers. You can give them copies on CDs. That's [a] pretty inexpensive [way to share that information], especially [with] your family doctor and your gynecologist. I think they'll love you for it. I really do. I think they'll appreciate having that information. [Almost] everybody ... can play CDs on their computers. And don't forget



to update it ... [with new prescriptions, medications you've stopped taking, and any newly developed allergies.]

So now we're just going to relax before we move [to the new room]. This [photo] was taken ... in Belize two weekends ago. My niece got married on the beach. She did the whole destination-wedding. I was sitting on our little casita [travel trailer] that we were staying in. The palms would just [swaying], and I thought it was so relaxing. So if you just watch trees sway, [and] just take that moment to take a deep breath, it really is relaxing. I think creating this survivorship plan will make you want to relax, because it's a lot of work to get it going, but then you're going to [be able] to relax a little bit. ...

**ANITA C. BROXSON,
MSN, RN, OCN:**

... A couple of words about the survivor plan are: There are things that you can do in being proactive to take care of yourself. So you're going to create this great plan. But you've got to do some things, too. So I hope nobody here smokes. But if you do, quit. I know that's easier said than done. But just quit. It didn't help you through chemotherapy. It impairs healing. It hurts your immune system. There is absolutely nothing good about it.

The other is just so easy. Eat right, exercise. No problem. Well, we all do that, right? What do we hear ... we've got to do ... three hours [of exercise every] week? I'm starting Monday. And sunscreen, absolutely. I think that people tend to underestimate the incidence and seriousness of skin cancer. You don't want to get through all this and then get melanoma, because that is no picnic. Treatment for breast cancer was bad enough. You don't want to add ... melanoma [treatments] to that.

Don't forget, when you get to [the recommended] age to [schedule] ... routine screenings: that colonoscopy at age 50 if not earlier, if there are any signs or reasons. Because ... there's [a] link in some people between colon cancer, ovarian cancer, breast cancer. So you want to make sure you're taking care of [your preventive care and diagnostic testing]. Any [symptoms] or changes in your bowels that are not totally resolving on their own need to [be] checked out. Certainly if you see blood [in your stools that is a serious symptom that needs to be checked out]. Nine times out of ten that [symptom is] not going to be anything, but you need to have it checked, and,

of course, to still maintain your well-woman checkups.

This was going to be the time for ... questions about that survivorship care plan, and we'll do that for about ten minutes. Then we'll go to the next section, the next part of the presentation. Since we had to move, I just want to make sure we have more time at the end for questions. So, any questions about the care plan or tips for creating it?

JENNA GLAZER:

No questions?

**ANITA C. BROXSON,
MSN, RN, OCN:**

None? Oh, here's one. Wait just a second.

WOMAN:

When do you suggest to begin the care plan?

**ANITA C. BROXSON,
MSN, RN, OCN:**

I would ideally say when you start treatment. If you haven't started, [you can begin recording information for your survivorship plan] at any time during treatment, certainly towards the end of that visit, when you're ending therapy. ... A lot of you may have already completed that part of treatment. You can still [start the survivorship care plan] now. ... You can go to the one online, and you can ask for a couple of different ... tools. But do initiate something now, as soon as you can. ...

WOMAN:

It's not really a question. I was just going to make a suggestion for you type A, anal-[retentive], [obsessive compulsive] people like me. I'm a nurse. I'm an organized freak. I started a three-ring notebook with the dividers — like [the ones] my kids use for school. I labeled one "chemo," and I labeled one [for] all my pathology reports. I get copies of everything: all my X-rays, my biopsies, my MRIs. ... Every time my doctor wrote for chemo [or other medicines], [I wrote down] what the medicines were, how much Ativan I got, and how much Decadron and all of that. Then I have another entire notebook that's just my EOBs from Blue Cross Blue Shield.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yes.

WOMAN:

They're all in chronological order backwards. ... As I got them in the mail, I started labeling them ... so I could tell you to the penny how much every chemo was, how much every —

**ANITA C. BROXSON,
MSN, RN, OCN:**

Wow.

WOMAN:

— Neulasta shot costs. I mean, it's a little crazy.

**ANITA C. BROXSON,
MSN, RN, OCN:**

But that's great.

WOMAN:

I think [it was] just for peace of mind, and if you have a husband like most husbands are, they're a little clueless when it comes to [finding] things ... I just have a list on a sheet of paper of all of my doctors and their phone numbers, if, God forbid, something happened, and he needed to call or something.

**ANITA C. BROXSON,
MSN, RN, OCN:**

... That's a great, great tool. I would take all those papers and scan them, [then save] them in PDF [format] ... on a disk or something, so that you also have an electronic version of that [information]. So [if] something happened to the notebook or anything, [you'd still have that information]. But that is wonderful. I know the Lance Armstrong Web site [<http://www.livestrong.org>] has [a link that will help you get organized, http://www.livestrong.org/site/c.khLXKIPxHmF/b.2662947/k.9791/Get_Organized.htm]. I've seen [three-ring binders] at some other conferences. ... But [a binder is] huge — [it's] a lot to carry around with you from visit to visit. Th[e binder is] what they've proposed. But you can create your own tool like that [in a lighter, portable electronic form]. ... The main thing is finding what works for you, and getting some of that key information in there so you can share it with the people who need to have it.

WOMAN:

I work on the clinical side of this. Not that this is going to help you now, but it may help somebody that you know: ... I recommend [that when you] first visit an oncologist, you take a tape recorder with you — [Editor's Note: Make sure to ask your doctor for permission before recording your appointments.]

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yes.



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WOMAN:

— because they're going to give you so much information, [and] you're only going to hear [one]-third of it. I can't tell you how many times I get calls and they say, "Well, the doctor said this, this and this." And I [reply], "No. Let me pull up her note and let's see what she said." What the patient thought she said was not what she said. So I have to go over this. I suggest that you [bring a tape recorder]. Then you can transcribe [what the doctor actually said]. Or you can . . . ask for a copy of [his or] her transcribed note . . . to put in your notebook from the very day [of your first visit to that doctor. That record will help you recall] . . . what you talked about, what your risk is, and what your recurrence-risk [may] be. Then start from there, because you can always get copies of it [made for your records, or to share with the doctor].

ANITA C. BROXSON, MSN, RN, OCN:

It's kind of like when you go into the hospital. . . . You may or [may] not be aware of this, but I know the RN would be: . . . When patients are admitted to the hospital, we start thinking about discharge the day they're admitted. . . . We start thinking about how we're going to get them out — what are all the things we're going to do while they're in the hospital to get them out of the hospital, and get them home. When you think about . . . going through your treatment, the whole purpose is to get you to that point of survivorship, [to get you to] . . . the end of treatment. [The goal is to] move you forward and keep going into the future, [to assure you] have good care and good continuity of care. Because with our nursing shortage, and more people being diagnosed, and [all of] us having to do more with less, [time is precious. As for] the chances of somebody saying, "Oh, let me sit down with you for a couple of hours and let's write out this plan" — that's not going to happen. That's why I want you to know about these plans and create something for yourself, for that continuity [of care].

WOMAN:

We want to take this information home to the girls that weren't able to come here.

ANITA C. BROXSON, MSN, RN, OCN:

Sure.

WOMAN:

I know that some of them are not going to go on the Internet. They're just not going to take the time, or they're not that Internet savvy. Is there somewhere they can get a hard copy of the form to take to their doctors, and work through it that way?

ANITA C. BROXSON, MSN, RN, OCN:

A form that might be on the Internet for completing? There's —

WOMAN:

Right, because I know most of the docs in our area are not doing this.

ANITA C. BROXSON, MSN, RN, OCN:

If one of you can go to one of the — at the bottom of that paper I have a resource: the *Journal of Clinical Oncology*. Patti Ganz [<http://jco.ascopubs.org/cgi/content/abstract/26/5/759>], wrote an article — she's kind of like the guru of cancer survivorship. And ASCO guidelines on the Web site, there may be some examples there of [survivorship care] . . . [http://www.asco.org/ASCOv2/Education+&+Training/Educational+Book?&vmview=edbk_de tail_view&confID=40&abstractID=525]. . . . If you have trouble finding that, e-mail me and I will find one and send [the information to] you. I have a couple of different kinds of copies. So I'll be glad to send you one with the reference so you'll have it, because you may have trouble pulling up a full text of some articles, where I can get access to them. But my contact is A-B-R-O-X-S-O-N at M. D. Anderson dot org. . . . Did any of you all stop by our table today with the pink tablecloth? It says the Young Breast Cancer Survivors Program at M. D. Anderson. I have newsletters there, and my contact information is on the back of the newsletter, as well as on my business cards. . . .

WOMAN:

. . . At the back of it, it has all of the [blanks to fill in] to put your specifics and your doctors' contacts . . . [and] keep as a history of your — . . .

ANITA C. BROXSON, MSN, RN, OCN:

Right. So that would be a good starting point. You would probably need a lot more paper to fill out your life history with cancer, but it's certainly a good place to start.

WOMAN:

I don't have a question. I was just going to add to what she was saying. I work on the clinical side also. You can check with your cancer centers . . . I know most of the ladies in here are survivors, and they're [probably] not on chemo right now. But a lot of the drug companies give out exactly what you're talking about — in the binder, like you created. A lot of them give those [binders out] as some of their freebie things that they give to cancer centers. So that's another option, because I've seen varieties of what you're talking about: the binder with the dividers, and even the little slip-in things that [hold] . . . business cards, or your doctors' names, or appointments. Everything. So . . . if somebody wants to get one of those you can. They're easy to find.

ANITA C. BROXSON, MSN, RN, OCN:

If you're in a major medical center, or you have somebody who's delivering lots of those things — that's a good resource.

WOMAN:

I live in a rural community, and we even get tons of them.

[Speaking simultaneously]

ANITA C. BROXSON, MSN, RN, OCN:

But rural, if they come out, one thing that's happening this year with the pharmaceutical companies is they're being very limited as to what they give us. . . . This PhRMA Code that went through January I has greatly decreased the amount of materials they can give out that go to patients. It's a shame, because I know it's certainly impacted us at MD Anderson. . . . But that's a great tool, when you can get them.

Maybe one more question, and we'll move on.

WOMAN:

Thank you. I have been struggling with — so, I've had three cancers in three years. I just was trying to scan the paper here on both sides, and . . . under surveillance, [it says to get a] history and physical every three to six months after primary treatment [for] three years, I'm just not — I have an internist and then an oncologist, too. But I'm post-treatment. So I was denied an appointment about eight months ago. I tried to get one with her because I was worried about stuff. Then there's a surgeon, and the reconstructive surgeon — but I'm post-treatment. I had a p53 mutation test,



because I'm the only one left in my family of four siblings and two parents. Everybody else is gone of cancer, [all of them died before turning] ... 46. But I didn't have the BRCA1 and 2 [testing]. I tried to get it, and I couldn't afford it. [So] ... I haven't yet gotten it.

I guess I'm feeling really stymied about — I can write out a piece of paper, and I can still remember all my dates and everything. But it isn't feeling like this is realistically what — when I call the doctor and say, “May I have an appointment? Do I need an MRI?” often I don't even get called back. It's a good [cancer center and a] teaching institution. But I think that maybe it's a combination of when the care is over with [and being at a prestigious hospital]. I wish I were at a community hospital where they were just nicer to me, because that's the part that ... they don't seem so good on. I feel like — the surgeon looked at me when I mentioned “treatment plan” as if I just had two heads, or that [I] was [being] really silly and frivolous.

**ANITA C. BROXSON,
MSN, RN, OCN:**

I'm sorry you're going through all that. Mm-hmm. Can you change where you're being treated, for one thing? Do you have to stay there? Because if you think you can get better care someplace else, I would investigate that. If you're in a teaching facility, I hope that — and I'm not going to ask where you are, but I know many of them, like ours, we have patient advocates, and we also have case managers. Depending on what role they play, it can vary from institution to institution. Or if you have something called a “patient navigator” [who could help in situations like yours]. It just depends on what they're called in your particular area. I would start with that person, and let them know what kind of trouble you're having.

This plan that I have for you there is very generic. For someone [with your history of cancer, and your family's history, recording that information is] going to be very different. I do want to stress [that], just like side effects, everybody's [post-cancer experience is different]. ... You're an individual. So what your needs are may be a little different than the person next to you. But this is just sort of a guideline, a place to get you started, to help you start thinking about a plan, gathering that information, organizing and getting everything in one place. So when you do move around [and change doctors and visit

different specialists], you've got some information for continuity of care. When you do move, your new physicians can request information [and you'll have specific details to offer them]. You know that from your previous physicians. ... I would certainly, definitely see if you can seek some treatment someplace else.

... Communication is a big issue. Some of my young women have said to me, “Even my closest girlfriends don't understand what I've been through ... They were my friends before, and we're just different now.” They're empathetic, but they don't get it. Others said, “Cancer has changed me. I may look the same [as I did before the cancer]. My hair is back — but I'm not the same person. My family feels the same way.” They said, “Should I tell people I've had cancer?” So, that communication is going to become extremely important, because you can't have any of your needs met without that good communication.

When do you communicate, and what do you communicate? First you need to know what your needs are: What are your communication needs? What is it that you need to have shared with someone else? What ... do you want to share? You don't have to share anything that you don't want to — you're not legally obligated. Be kind to yourself and give yourself a break. Say [to yourself], “Okay. I don't have to tell everybody ... that I've had cancer,” or when you go to a new job, just keep it private. You don't have to share everything.

Then don't try to be Superwoman ... as you're talking to other people. My idea of Superwoman is somebody who bakes anything from scratch. (Laughter) ... It might not be [to you] — everybody's got their own idea of Superwoman. But, give yourself a break as you move back into the world of the this extended survivorship, and just do some self-reflection. See what it is you need, and then ... you're going to need to communicate those needs to others.

Consider the fact that you're entering this new phase of cancer care — that extended survival phase. Your contacts are going to be less frequent with your healthcare providers. You may need to change doctors. You may need to change centers. But we know to expect that [these things are] going to happen. The further you are out, the less frequent your visits are going to be. ... There's a tendency to hesitate, at least from what the young women have told me in our meetings. They don't want to call in-between meetings. They feel like they're bothering the doctor, ... their nurse or

anyone [else who answers the phone] when they call about whatever the complaint might be. They're afraid that they're going to sound like a complainer. I think what we would tell them is: Call anyway. Rather to call and feel better than to sit and worry yourself to death about something. It may be that general practitioner, the family doctor, or the GYN that you're seeing; instead of the oncologist and the nurse practitioner for follow-up. They need to know, from that plan that we talked about earlier, about your history and what you [were diagnosed with, what you took for medicines and what you experienced]. I think they're going to really appreciate [that information] ... because as clinicians, we don't always hear what you're thinking unless you tell us. We don't know what your needs are. You have to be able to tell what those [needs] are, but you have to identify them first.

I know that moving forward with these practicalities of life is a bit difficult. It's a lot easier said than done, like one of the first slides I had up that said, “The doctor said go back to your normal life.” We've all heard this. Well, what's the new normal? What is normal? That's going to be an individual decision. What do you consider to be your normal life?

We know there will be concerns about inherited gene mutations. On that other handout, it [showed] who should be tested. You may know breast cancer survivors who — maybe a parent, a mother, an aunt, a grandmother — ... had cancer many years ago when they weren't doing genetic testing. You may want to inform them about that if you haven't already. But that's something I know you're going to be concerned about.

What impact this cancer has had on your career, your fertility, what life choices you're going to be making, and learning how to live in the moment: There's a Web site called <http://livingmindfully.org> — just all one word, livingmindfully. ... Micki Fine [MED, LPC] started this group. ... There's some advice on her Web site. You can actually subscribe to her [monthly] electronic newsletter ... nice messages [and] ... very practical advice on how to live for today. We tend to lose a lot of time by worrying about tomorrow and worrying about what we did yesterday. But learning to live with today is going to be much more beneficial to you than losing today because you've been worrying about tomorrow. So that's what she calls living in the moment.



Have any of you heard of living mindfully or mindful living before? It's used in stress reduction. I actually started a class [on the subject], but I got too stressed about getting there. (Laughter) I know — that's terrible. But I said, "Oh, I'll start that next semester. I'll try that a little bit later." You have to be ready to be in the moment, I guess. But living in the moment or learning to deal with today does help with dealing with that fear of recurrence. You start focusing on now, instead of trying to worry about that recurrence.

When you're trying to communicate with your providers or your family or anyone, remember what it is you want to ask. . . . Create that notebook. Place it in a safe place. Make sure that you put your plan in it. You can't start the notebook and then not do something with it. This notebook is not going to develop overnight. I would suggest sticky notes. Some people like notes. Some people write them other places. I know I'll have yellow sticky notes outlining my computer at work. But when you think of something, write it down. Maybe keep a page in the notebook that's just for stickies and say, "I know I want to get this information or that information," and add it to your plan. If it's a question you have about healthcare insurance or legal issues or employment issues, write it down and put it in that notebook. Make sure you bring it with you to your next visit.

List any of those new medications in that notebook. Organize it before your next visit, because your providers are going to be really appreciative [of your organization. They] know you are more likely to have your questions answered, [and that they can better serve you], if you [are] . . . organized. . . .

Remember: you didn't go through cancer treatment without any help. At least I hope you didn't. I hope that you had social workers or case managers or some [other] . . . navigators in your area who could help you get through the system; or those who could help you with the things that were difficult. [Support during cancer is imperative] whether it [is for] issues with employment, with FMLA [Family Medical Leave Act], with depression or anxiety, with sexuality problems or any concerns about sexuality during or after treatment, and . . . resources for legal and insurance. Case managers are a good resource for learning about your rights with employers, and also helping you through the maze[s of] insurance . . . [and] family. Your social worker can be a . . . [guide] giving you good tips [on how to] . . .

communicate with your family. . . . You're not really the same person now that you've completed treatment — or do you feel like you're the same person you were before breast cancer? Who feels like the same person? One? That's great. I'm glad.

. . . I think I told you [a] quote [earlier today from the woman who said] . . . "My hair's grown back. I look the same. But I'm not, and they just don't get it." That's very difficult for family members. One young woman said, "The kids look at me and they think, 'Well, my mommy's . . . the same. She can go out and she can do all these things with me.'" Well, that's the time to communicate [your] limits, to know what your limits are — figure out what they are [before you communicate them to others]. Then take some time to be open with your family and explain just who you are right now at this point in time, and that you're going to improve over time, that [the] fatigue will [decrease over time]. Whatever the issues are, [those challenges] will [decrease] over time. It might take a year. It might take two years. . . . Let them know . . . that things will get better. Talk about the future, and moving forward as you get better. [Talk about] things you're going to be able to do again with your children or . . . your family.

Children, particularly, need some good, age-appropriate communication. I don't know if I have any teachers in the room. Do I have any teachers — any elementary teachers? Do you remember learning about Piaget's [Theory of Cognitive] Development, [discussing the] levels of development in children? [At] . . . certain levels [children are] . . . abstract thinkers and concrete thinkers. Children can only take in so much information. It depends on their age and their development. So a school counselor is a great person to talk to . . . to learn how to communicate with children, whether they're your own children, nieces, nephews or [any other children] . . . you may be in contact with. [Learning about developmental stages will help you communicate] . . . exactly what's going on with you, so that they're not concerned. Children worry about their parents. I'm sure you probably know that. Even when you're all grown up, your grown-up children still worry about their parents. But be [as] honest and open as possible.

We have a program at M. D. Anderson called KNIT . . . Kids Need Information Too. It was created by a young woman named Martha Aschenbrenner, who is a young breast cancer

survivor. She works with Child Life at M. D. Anderson, so she works with . . . pediatric patients. She developed this program on talking to children [from her experiences of] having children . . . when she went through her breast cancer, and then doing what she does at MD Anderson. In our Web site for our young breast cancer survivors' program, all our newsletters are archived there. I can't remember which newsletter it was. I think it's about a year ago. But I have a whole section in that newsletter on her advice on how to talk to children. I know it's just another Web site. But if you pick up our newsletter . . . and you look . . . at the Web site and some of the archived newsletters, you will see this program called KNIT. It really does give lots of good tips in how to talk to children and what's appropriate [to discuss with kids].

But spend, too — and this sounds like, you know, not rocket science — but take . . . a little bit of extra time with them and let them know they're still special, and that there are tasks that you are going to be able to do with them. Do what you can, and let them know what you can't do, . . . but [remind them that] you will do things with them. It may be . . . arts and crafts. It may not be running and playing soccer. But [show them] that there are things you can still do. Spend quality time with the children [in your life]. Make future plans: summer vacations, spring break. Let them know, "We're going to go on vacation this summer," whether it's a weekend away, a day away, something that's special, that keeps them thinking about what's coming next. [Plans that help them keep] moving forward, and focusing on the future. . . .

Employment: As I said earlier, you're not legally obligated to tell your employer about any cancer history unless it directly impacts your ability to do your job. If you do a job that requires . . . some fine motor skills and you're having some neuropathy, well, that might affect your ability to do your job. But in most cases it's not going to affect your ability. But you need to know what your legal rights are, because you definitely have legal rights.

So, how can you learn about these? What if you're having trouble with this? . . . [One] great resource [is] . . . Cancer Legal Resource . . . [<http://www.disabilityrightslegalcenter.org>, . . . (866) THE-CLRC or (866) 843-2572]. They talk about insurance coverage, employment, discrimination, any problems with access to health care as a cancer survivor or as someone actively undergoing treatment. It really doesn't matter where you are in that phase of treatment — this is a great



resource, and it's free. They can provide confidential information and resources on legal issues to survivors' families [and] friends. They [define] "cancer survivor" [as] any[one] who's got a [recent] cancer history, or who's had cancer in the past. Remember that definition I showed you earlier? ...

Another [great resource is] Cancer and Careers [http://www.cancerandcareers.org]. ... There are some free services on here. It looks [like] kind of a busy webpage, but you can take a little time to ... find something that's applicable to you. [For] those who don't have access to Internet, I would encourage you to print this information and bring it home. [If you do have Internet access], give [this information] to others who may not be able to access it. But if anybody can get to a public library, they can get to a computer and look up information that way.

... [A quote that may help inspire you is from] Hoda Kotb, [and it is] about moving forward. Does everybody know who she is? ... She's a young breast cancer survivor. She said, "Everything that was important became totally clear, and so did the negative parts of my life that I needed to let go of if I wanted to follow my new mantra: Go forward, forward, forward." And if you go to just msnbc.com you can Google Hoda Kotb and her whole story is there [http://www.msnbc.msn.com/id/26967472]. She tells a story about when she was diagnosed with breast cancer a year and a half ago, and she had to take some time away from work. When she came back, she had a new outlook. She said that going through cancer made her realize how strong she could really be. She just marched right into the producer's office and said, "I want to be a co-anchor or co-host following Kathie Lee [Gifford]." ... She said she would have never had the nerve to go in and ask for that big promotion ... had she not [gained emotional strength through] ... her cancer. ... She said, "Having the cancer history did not deter me one bit from going in and asking for that promotion." And she got it. So she actually thanked her cancer for giving her [a] new job.

I guess it's time to talk a little bit more about whatever you all want to talk about. [This picture shows] ... some young women at one of our workshops in Houston. ... They're all laughing here, you can see. The topic that particular day ... was sexuality. They were laughing at Mary K. Hughes. Did anybody hear Mary Hughes' talk today? ... I think [she] did palliative, or ... end-

of-life issues. She's doing two or three while she's here. She's one of our clinical nurse specialists in psychiatry. I think she did anxiety or depression, maybe last night. She also does a great talk on sexuality. So they were laughing at Mary here.

And [here are more photos from] ... Belize. So, deep breath.

WOMAN:

Is that Ambergris Caye, [Belize]? ... Where were you in Belize?

**ANITA C. BROXSON,
MSN, RN, OCN:**

... Ambergris Caye — yes. You have to get around on golf cart. ... the taxi meets you, but so does a golf cart. Then you realize you need the taxi because of your luggage. ...

One other thing before we get into discussion: How many are from Texas? Just a few, five, six. How about south Louisiana? ... I'm from Louisiana? Where?

WOMAN:

Lafayette.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Ah. I'm from New Orleans, when I say it right. I had a daughter in Lafayette and a daughter in New Orleans. ... Oklahoma — driving distance from Houston? We're getting closer. We're getting closer.

Houston's not that far. But we have [a free] seminar on a Saturday in April ... [see page 6 of http://www.mdanderson.org/education-and-research/departments-programs-and-labs/programs-centers-institutes/beth-sanders-more-program/newsletter/bsmp-news-winter09.pdf]. We have three phenomenal speakers. It started out with one [speaker], and then it kind of blossomed and got away from us. But the first one is Julie [K.] Silver, who is a physiatrist and a young breast cancer survivor physician from Harvard. She's written a lot of books on healing after cancer — [on] moving forward and getting on with your life. So have her children. They've written one book called *Our Mom is Getting Better* and another one [called] *Our Dad is Getting Better*.

Then we have Micki Fine, who is with livingmindfully.org — the therapist that I told you about earlier who talks about living in the moment and stress reduction. Then we have a comedienne from Manhattan who's going to do some innovative improvisational comedy and involve the

audience. I don't quite know how she's involving the audience, but it's going to be interesting.

Then we do two post-workshop events. One is new to me, and it's a ... nonprofit organization called Just So You Know [http://www.just-so-you-know.org]. ... This is a woman whose best friend had breast cancer. She started a group where they videotape you and your friend, or you and your spouse, or you and a favorite girlfriend, person, someone — and you [record a] chat for 30 minutes. The 30-minute chat might be about what you did as kids. She and her friend talked about the antics and the trouble they got into in college. Maybe not the trouble too much, but she said, "We just laughed for 30 minutes, and we taped it." Then she said, "We just play it back, and when you're feeling kind of down, it just makes you laugh." They have a whole list of things on their Web site that you [may] want to talk about — conversation starters. So it's an upbeat kind of thing.

The comedienne who's coming is very familiar with the program, and so her intent is to get everybody laughing and goofing off and talking about it. Those who want to make a videotape can [record] after the conference. I'll only be able to take so many to do the tape, but there will be information about that on our Web site. The other thing we're going to do is some art-collage, which we've done at workshops before. It's a lot of fun.

Anyway, ... if you can make it to Houston, you're certainly welcome. And all the contact information is [available].

Any questions?

WOMAN:

Hi. My question was in regards to the [survivorship] plan. I did a lot of research of my family history for genetic testing. In the medical field, what are they doing as far as medical records? I understand that after a certain amount of time, they just discard them.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Discard them?

WOMAN:

Yes.

**ANITA C. BROXSON,
MSN, RN, OCN:**

No.

WOMAN:

Yes. In Philadelphia, after eight years they discard it. So I had a —



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**ANITA C. BROXSON,
MSN, RN, OCN:**

We don't discard medical records. We've got medical records that go back to the beginning of M. D. Anderson in 1940-something.

WOMAN:

[Inaudible]...

**ANITA C. BROXSON,
MSN, RN, OCN:**

Are you concerned about results from genetic tests?

WOMAN:

Yes. I, of course, have breast cancer. My grandmother died of ovarian cancer, and I was trying to get her pathology report. They told me since she died in 1985 [and] that the records were destroyed. I find that very disturbing that in the medical profession, even if they want to discard them, can't you call a family member on this plan and say, "Look, here's your opportunity to either get these records back or we're going to destroy them," because we don't have —

WOMAN:

What hospital was that?

WOMAN:

[Inaudible]...

WOMAN:

That was the other thing. They said that they moved them off-site, and then I had to call this other facility.

**ANITA C. BROXSON,
MSN, RN, OCN:**

They will move them off-site. But they're not, to my knowledge, not destroyed.

WOMAN:

Yep.

**ANITA C. BROXSON,
MSN, RN, OCN:**

They should not be destroying them, because they can go back and they'll want — a lot of times different things come up that they want to go back and check those records, [such as] ... your [situation]: looking back at cancer histories and things back in families. I don't know about that institution. I just know that's not a general rule, to go back and destroy the records. Boy, is that a good reason to start your survivorship plan —

WOMAN:

Yes.

**ANITA C. BROXSON,
MSN, RN, OCN:**

— if you think somebody's going to destroy the records. I don't know about anybody destroying medical records. ...

WOMAN:

I've actually said, "I will physically go in and help you go through the files." I can't get [records for] my grandmother ... on my mother's ... side. ... Her mom died of ovarian cancer, and two of my aunts ... [Inaudible] have ovarian cancer. Now I have breast cancer, and I can't get any [of the historical] pathology reports.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Why don't you look at that legal Web site [<http://www.disabilityrightslegalcenter.org>, <http://www.lawhelp.org>]?

WOMAN:

Okay.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Give them a phone call. ... and see how much they can help you get to those records.

That brings up another point about having good communication. ... After Katrina hit New Orleans, we had patients showing up at [M. D. Anderson] saying, "I'm here for chemo." [And we would reply], "Okay, what were you getting?" [And they would say], "I don't know." [We'd ask for records, and they didn't have copies of their records.] ... So many records were totally lost, and then completely, forever gone. Women were coming into the clinic at M. D. Anderson saying, "I need treatment." What a nightmare. You can imagine. Even if they knew what they were getting, they could say, "Oh, well I was getting FAC," [Fluorouracil, Adriamycin and Cytosol] or, "I was getting weekly Taxol," or, "I was getting" this or that — they didn't know dosages. They didn't know where they were in the plan. ... Any natural disaster could happen that could destroy medical records. So that's just another good reason to have some good record-keeping for yourself, to kind of protect you against [any unexpected events]. ...

WOMAN:

I'm just going to say I had the same experience in Colorado. [Inaudible] ... my grandmother's medical records, too. I even knew her doctor's name.

**ANITA C. BROXSON,
MSN, RN, OCN:**

You tried to get your grandmother's medical records?

WOMAN:

Yes, because I wrote a book, and so I wanted to make sure I had my facts straight. My grandmother died of breast cancer. I even knew her ... oncologist's name, and I still couldn't get access to any — they said those records were destroyed as well.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Wow. I just don't understand that, really. I can't help you with that. I just know what we do [at M. D. Anderson], because I've looked at records that are [from the] 1940s. ... I'm sorry. That's really sad that that happened. ... There's no way you're going to ... get them. ... if that's the truth — if they really did destroy them.

WOMAN:

Exactly. That's my next question, because I've kind of been on the planet long enough to know that just because someone on the phone told you that —

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yes, [that] doesn't mean it's so.

WOMAN:

— doesn't always mean it's so.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Here's another option. Have you heard of state tumor registries? It's by [federal] law — the institution where cancer patients are treated have to report to [a] state registry. It's called the tumor registry. Each state has one. By law they need to report the number of cases. They have to send that information to the registry. It's within the first year. I think they start sending it out — ours does it after six months, because what they try to send is a complete picture of — say you walk in today and you're diagnosed with lung cancer. The tumor registry folks at our institution will start collecting information on this individual six months from now, because they want to look back and capture most of the treatment that [occurred] ... in the first six months. At approximately one year after that person walks in the door, a complete record has been generated on [his or her] history and sent to the state tumor registry.



This is how a lot of these statistics come up, how we know how many people got cancer in what communities. That's also how they identify cancer clusters, where you might have a community and suddenly you see lots of different people developing cancers. They'll notify the CDC [<http://www.cdc.gov>] [and say], "Here's a community you need to go out and look at, because we're seeing an unusual number of cancers."

But the state registry ... should have information on anyone who's had cancer in the state, [anyone who was] diagnosed more than one year ago. They don't give that information out to just anybody, but the information is there. So that might be a resource that you could get information from, especially [if you have support from an attorney or a legal agency such as Law Help <http://lawhelp.org>]. I just thought of that, because the tumor registries have all that information.

WOMAN:

There are also federal regulations on laboratories retaining paraffin blocks —

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yes.

WOMAN:

— that are used for biopsy, and the slides made from those blocks.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Right, right.

WOMAN:

They have to keep those paraffin blocks for some years, and the slides, I believe, forever.

**ANITA C. BROXSON,
MSN, RN, OCN:**

That's right.

WOMAN:

I don't know what you would need if you're a descendant of someone who had those [records. I don't know] what [information would be helpful from that preserved information. Would it be helpful to] ... have someone look at those slides again or make more slides from those paraffin blocks to get that diagnosis?

**ANITA C. BROXSON,
MSN, RN, OCN:**

To get that, yeah.

WOMAN:

I don't know what you would have to do to get that information. But those things are kept for years, and years and years.

**ANITA C. BROXSON,
MSN, RN, OCN:**

I'm so glad you mentioned that. That's great. That's a great idea, a great resource. Probably the ... easiest way to ... find out if you want to go that far is ... first of all, the information about anyone who's deceased is no longer protected by HIPAA. So ... [HIPAA won't stop you from getting information about individuals who are] deceased. What you can do is work through one of the advocacy groups ... [focused on people with breast cancer, <http://www.lbbc.org/resources-links.asp#Advocacy>]. We have so many advocacy groups — contact them and see if they have some resources.

I'm saying it's not going to be easy. You're going to have to ... be like MacGyver. Well, that's a little bit old, MacGyver. What is [a more recent reference], "CSI"? I don't know. I don't get to watch too much television these days. I'm a doctoral student. Next year, PhD. Yay. But, anyway, it's going to take some sleuthing and some digging to get that information. But I think it's possible by using a combination of efforts and some persistence [and] patience. Somebody who's "type A" might really like to do this sort of thing.

Any more questions?

WOMAN:

Who would you recommend [as the] ... best medical person to help us put together this plan? I have a medical oncologist, surgical oncologist, radiation oncologist, general practitioner and OB [obstetrician]. So who would be —

**ANITA C. BROXSON,
MSN, RN, OCN:**

A nurse practitioner? ...

WOMAN:

[Inaudible]

**ANITA C. BROXSON,
MSN, RN, OCN:**

I would say your medical oncologist [would be the best choice]. Is there a nurse in the office that you have good communication with? [Or], maybe the [way to decide] is [to figure out] who you have the best rapport with. If there is a nurse in the office that you have really good rapport with, I would start there. If you don't, [or if] you're not

sure, ... start with the medical oncologist and let him [or her] know that you want to start gathering this information. Maybe do it in bits and pieces. You know, don't [start off with] ... this whole thing and say, "I need all this information now," because that's not going to happen. But say, "I'd like to at least get this part of it done — all my surgeries."

Go back into your records, like she went back to her EOBs [explanation of benefits]. That ... [information may] ... help you jog your memory [on details for your survivorship plan]. But go back and write down as much as you can do on your own. Then ask [your doctor] to help you fill in the blanks. Because if you just hand [over your form] and say, "I need this filled out," they're going to look at you like you're crazy. But if you go in with something started, and a plan, then I think you're likely to be more successful in getting that completed. Wouldn't you agree, Betty? Betty's a nurse practitioner at M. D. Anderson in breast medical. ... She will give copies, transcriptions and everything to the patients. ... [I'll] let her talk to you a little bit more about that.

BETTY HARRIS, WHNP, MSN:

When I have a patient [who] requests anything, I go straight to the [archived] documents. I pull the pathology, I pull their report of surgery — exactly what was done to them. I pull their first visit where we've discussed what their plan-of-care is, [including all details] for their treatment. I pull every x-ray they have [on record]. I give them a copy of everything, if they want it. They ask for it; they get it. So, it just [gets] easier. My brother was treated [at M. D. Anderson]. I pulled [all of] his record[s]. So I do that for all of my patients [who] want it, and just hand it to them. ...

**ANITA C. BROXSON,
MSN, RN, OCN:**

... My sister was treated at M. D. Anderson last year, and [her tumor] turned out to be benign. ... I wanted to get her all her records to take back to New Orleans ... [because all of her records] ... got wiped away [during Hurricane Katrina]. But she had come to get a benign thing taken care of. I said, "Well, I know what you need, to take all this back with you and ... start over with your medical records." So I said, "I know, I've got access. I can just go print everything." So I said, "Maybe I'd better go through the proper channels." ... We went down to [the] medical records [department] and waited an hour. I'm thinking, "I really should



have just done this myself." Like I said, "But maybe there's something different that they're going to give her that I can't do." So we wait this hour, and I sit there and watch this clerk pull up the transcribed notes and hit print on every single thing. That's exactly what I could have done in the office.

But not everybody has electronic medical records. So [in some hospitals a records request means waiting for] . . . copies and things like that. It really varies from [one center to another]. . . I would hope that many of you have a nurse or a PA, someone in a doctor's office that you've been able to connect with and had good communication with. That [person is the best one to start with], . . . because [that person is] going to understand your plight and be your friend [in] helping you to collect that. But, again, bottom line is go in with as much [information] as you can from your own memory and [make the process] more of a fill-in-the-blank kind of thing. It's not [likely to be a situation where] . . . they can just snap their fingers and print everything off for you. . .

WOMAN:

Hi.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Hi.

WOMAN:

Is the information from medical records sufficient, or [should I be requesting] additional information from the . . . surgeon, oncologist [and] radiologist?

**ANITA C. BROXSON,
MSN, RN, OCN:**

The medical records should have all the surgeries you had, the dates. It should have your chemo dosage. It should have everything in it.

WOMAN:

So I don't need to go to —

**ANITA C. BROXSON,
MSN, RN, OCN:**

If you want to just get a copy of all your medical records, you might have to pay for a copy, but you can request that copy. You may have a hard time understanding it. But if you do [need help understanding your records] . . . you could ask for help with that. But [all of the information needed for your survivorship plan] should all be in the medical records.

WOMAN:

∂Thank you.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Mm-hmm.

JENNA GLAZER:

Do we have any more questions out there?

WOMAN:

Hi. If you're at a small community hospital, or a big community hospital — not as big as M. D. Anderson . . . with all their resources — each physician should give you a copy of every test.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yes.

WOMAN:

I'm a doctor. I hear a lot of doctor bashing. I think it's very embarrassing. But, I mean, every test you have — I used to take out gallbladders, and no one cares if they've got gallstones or not. . . . Give them a copy — your doctor should do it.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yeah.

WOMAN:

You might have to chase each little center and get copies. And sometimes [when the medical center is] small they charge . . . to copy a whole bunch of stuff.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Right.

WOMAN:

[They are legally limited in how much they can charge.] [Editor's Note: The cost may vary by the laws of your state.]

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yeah. Yeah. We don't want to doctor bash. We love our doctors.

WOMAN:

Oh, they deserve it sometimes.

**ANITA C. BROXSON,
MSN, RN, OCN:**

But doctors are busy, as you know. That's why I'm saying go in with as many blanks filled in as you can, and have someone help you finish filling in all of those blanks.

JENNA GLAZER:

Hold on. I'm coming to you.

WOMAN:

Thank you for taking [my questions] a second time.

**ANITA C. BROXSON,
MSN, RN, OCN:**

That's okay.

WOMAN:

I'm going out like on a limb here. I know I'm the only — I assume I'm the only one who cares about this, so I apologize. I haven't — so, I'm just going to say it. So I had bilateral mastectomy 16 months ago. The cancer was — I was diagnosed through pain in one breast. And it's — I'm not staged. It was DCIS on both sides, but it was eight centimeters in one breast. So I can understand why they didn't say anything before the bilateral mastectomy about pain afterwards, because I believe in palliative effect, and so I can understand that there's an inverse of palliative effect.

I've had physical pain that's of the same character — intellectually, at least, as far as I know — for all these 16 months, 17 months since in the reconstructed breast. I'm on a seesaw. Some days I'm terrified, and other days I'm all put together. I've looked at both sides of this flier over and over and over. I don't know who to go to. . . . [Is there] . . . somebody in the room who knows somebody who . . . has been told that the physical pain may be phantom pain syndrome or phantom limb syndrome? . . . [That's what] . . . I was told in response [to my concerns]. I sure would love to meet [someone who had a similar experience] . . . I look through the indexes of the books in the Borders table out there, and I can't find "phantom limb syndrome" [in] any breast care book.

. . . I'm at a good teaching hospital in Philadelphia where I think the quality of the care — while you're a patient and there's medical care to be given — is very good. But I think that afterwards, it sort of fell apart — at least for me. They're very busy. They just got magnet status. So I'm ashamed to say I feel like I'm a problem patient who's just been — and nobody knows where to send me. Maybe it [is] phantom limb pain, but the word — [Editor's Note: There are many resources on pain, but here are two to get you started: http://www.lbbc.org/content/newsletter-article/living-well-managing-the-acute-side-effects-of-treatment.asp?section_tag=G; and <http://www.cancer.gov/cancertopics/life-after-treatment/page4#c3>] . . .



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**ANITA C. BROXSON,
MSN, RN, OCN:**

Do you have a pain clinic?

WOMAN:

But the word maybe was actually the more frightening word than the phrase phantom limb —

**ANITA C. BROXSON,
MSN, RN, OCN:**

Oh, yeah, yeah.

WOMAN:

— because maybe not. Since it's the third cancer in three years, and last year my only other living family member, my younger brother, died of pancreatic cancer, you know, so the word, maybe, was I guess what freaked me out.

So I've been to see the surgeon and realized that that's not her purview. She all but just put her arm out like that, "I'm done with you." I understand that. I did see — but I just — when you end up and your mind, your brain is a hamster that won't go off, that won't take a rest from its little track, like me right now, what do you do? Where do you — that's I guess what —

**ANITA C. BROXSON,
MSN, RN, OCN:**

Again, can you see somebody different?

WOMAN:

I could change —

**ANITA C. BROXSON,
MSN, RN, OCN:**

Would you be willing to go to a different doctor and get another opinion?

WOMAN:

I can't go to a different doctor at that institution ... [Inaudible] ...

[Speaking simultaneously]

**ANITA C. BROXSON,
MSN, RN, OCN:**

Yeah.

WOMAN:

I can go — so I can go to — I'm going to what is considered the best hospital in the Philadelphia area for the — so I can go to a different hospital. I'm in walking distance from that hospital. I even live in the neighborhood in order to be near them. I was a patient there with malaria 25 years ago, so I thought it would be best to stay at that hospital. But, again, recently I've thought maybe I should just go to a community hospital without any famous name attached to its care quality, just so that they wouldn't say, or look at me, say or look at me like I'm just either a problem-patient, or it's all in my head or it's — they don't have time for it.

**ANITA C. BROXSON,
MSN, RN, OCN:**

Right. I don't know how to answer your question. I really don't. I don't know if anybody has any advice for you here. All I can tell you is when you're not happy, no matter what it's about, go someplace else if you possibly can. I couldn't begin to hazard a guess why you have pain. It may be post-surgical. A lot of nerves get cut, things like that, that can continue to give you problems. You need a specialist to look at you and to help you feel better ... emotionally and physically. So perhaps they can just refer you to — if it's a big teaching hospital and they just have all this status, I would think they probably have a clinic that addresses just what you need, like a pain clinic. Just ask to be evaluated and let someone in the pain clinic talk to you. I mean, it's a place to start.

JENNA GLAZER:

I'm so sorry we don't have time for any more questions.

On behalf of the presenting organizations, Young Survival Coalition, Living Beyond Breast Cancer and [Susan G.] Komen for the Cure [<http://www.komen.org>], I want to thank Anita Broxson for this great and informative workshop. I hope that everybody really enjoyed it. ...

[END OF TRANSCRIPT]