



# Navigating the System: What You Need to Know

Kathryn Noble, MSW, LCSW

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## ELYSE SPATZ CAPLAN, MA:

Good evening, everybody. Welcome. We're glad all of you made time [in] your busy day[s] to come to [a] Living Beyond Breast Cancer networking meeting, "Navigating the System: What You Need to Know." Obviously, this is a really timely topic.

I've got a couple of things I'd like to tell you about. Number one, I should introduce myself, because I see a lot of new faces in the room. . . . My name is Elyse Spatz Caplan, and I am the director of programs and partnerships at Living Beyond Breast Cancer. I've been with LBBC close to ten years now.

We're just delighted that our networking meetings are reaching women in different parts of [the] Philadelphia area. We hold them about six times a year in the Conshohocken area. . . . We've been holding them in the Cherry Hill [Public] Library for women who live across the bridge right here, in the Southern Jersey area. And last year we . . . started to hold them in Center City, Philadelphia. We're really delighted that we can [make these events more convenient, and] reach women who are living and working [in the Philadelphia area]. We've heard that lots of women who live outside the city are happy to come. I can see from our attendance that we're really reaching a lot of new people, and connecting them to the resources that we have at Living Beyond Breast Cancer.

. . . The topic resonates with me, because 18 years ago I was diagnosed with breast cancer. In 1991, there were no patient navigators. There wasn't even a discussion going on about how to . . . really get yourself through the system. The social workers did a great job giving patients support, [but navigating the system has] . . . changed over the years. So for these 18 years, I've really seen the paradigm shifting in health care, as it relates to cancer care. So I'm very pleased to see that [today there is] more of a patient-centered approach to health care, where women affected by breast cancer actually can ask questions, and have

a dialogue with their oncologist and their healthcare team. [Breast cancer patients now] have more of a role in . . . treatment [choices], because there are more options available to treat breast cancer today.

So, [all of] you need to be the most empowered and informed consumers of health care, so that you're equipped with the questions to ask, to get the answers you need. Also, with health care and insurance companies changing over time, we really do need help navigating the system. It's not always easy. The last thing you need after getting diagnosed with breast cancer is to have to deal with multiple phone calls to insurance companies, to doctors' offices, [and to be tasked with] getting . . . appeal [letters from your doctors] to [convince insurance companies to] cover [procedures and medicines that you need, but that] . . . may not be covered [by your insurance plan]. It's just an emotional drain. We want you to be informed and educated, so that you can empower your healthcare team to . . . help you get through your treatment and beyond.

I would like to tell you a little bit about your speaker. Kathryn Noble is an outpatient oncology social worker at the Kimmel Cancer Center at Thomas Jefferson University Hospital. Katie has spent the majority of her social work career in oncology, and has been active in both state and national oncology social work organizations. She was on the faculty of the Association of Oncology Social Work's annual conference, [which] was held in Minneapolis, Minnesota. [She] was [also] a board member and conference chair of the Florida Society of Oncology Social Workers, and completed an end-of-life care certificate at Smith College in Massachusetts.

Along with providing counseling, case management and support groups for cancer patients, Katie is also active in planning programs for young-adult cancer patients; working with head and neck cancer and facilitating grant-funded peer-

support program for doctors, nurses and other professional caregivers.

So, without further delay, please welcome Katie Noble. [Applause]

## KATHRYN NOBLE, MSW, LCSW:

Thank you. I'm Katie Noble, and I'm an oncology social worker with the Kimmel Cancer Center at Jefferson. I'm here tonight to talk to you about navigating the system. We are going to be talking about the medical, emotional and financial challenges of breast cancer.

Our objectives tonight are really to address the psychosocial impact of a breast cancer diagnosis, [and] to define the terms "oncology social worker" and "patient navigator." I'm sure you've heard those [terms]: Sometimes they can be confusing. You might not know where to find one, or what they do. So we're going to talk a lot about that tonight. We're also going to talk about the . . . challenges that can come up in a breast cancer diagnosis. And we're going to talk about the resources that are available — a lot of that is going to be directed by your questions.

One thing that's important to know, is that I may not have an answer to your question. If I don't, then I definitely have some [business] cards here [with my contact information]. I can get your number, or you can call me, and I can try to find out [the answer to your question]. Also, as a social worker, I often refer people out to other organizations. If I don't have the information, or if I can't help, then one of the things I do is refer people to other places that can [help].

I want to start [with a comparison of goals]: . . . Doctors and nurses worry about how cancer affects your body; oncology social workers worry about how it affects everything else. How it affects your emotions; how it affects your body image; how it affects your relationships, your employment, [and] your finances. As you know, cancer really isn't just a medical situation. It affects every aspect



of your life. And that's why, in most cancer centers, you'll find a social worker there to help you adjust to the other things that are involved. If you go to the doctor for a sore throat, you're not going to find a social worker there ... because you [can] adjust easily to a sore throat. But in a diagnosis of cancer, there's usually someone there, hopefully, to help you get through.

I wanted to start by talking about some of the psychosocial issues that may be involved in a cancer diagnosis. That's where I was talking about how [oncology social workers] worry about everything else. Some of the issues that may come up are employment concerns, financial issues, worry about your loved ones, anxiety or depression, body image issues, fatigue, transportation, insurance. Does anyone — has anyone had any of these experiences? You can raise your hand. Yes? [Laughter]

Are there any [issues] that I'm leaving out? Yes.

**WOMAN:**

[Inaudible]

**KATHRYN NOBLE, MSW, LCSW:**

Communication with your doctor.

**WOMAN:**

And then support, your support system.

**KATHRYN NOBLE, MSW, LCSW:**

Your support system.

**WOMAN:**

Also, I don't know if it would be under image ... hair [loss].

**KATHRYN NOBLE, MSW, LCSW:**

Your hair loss?

**WOMAN:**

Maybe also having access to wigs, or support like that as well.

**KATHRYN NOBLE, MSW, LCSW:**

So body image and hair loss, as a result of treatment — treatment side effects.

**WOMAN:**

Also maybe employers [are] being very [discriminatory], because of missing many days of work. ...

**KATHRYN NOBLE, MSW, LCSW:**

Okay. So, what your employment rights are, and a lot of time — and we'll get into that more later — but working with your human resources department, and knowing what your rights are, and what's available to you.

**WOMAN:**

More related to the medical side of things also, just putting together your medical team: who they should be, what roles they play.

**KATHRYN NOBLE, MSW, LCSW:**

Okay.

**WOMAN:**

How many of them are there? And how do they communicate with each other, so that everybody's on the same page?

**ELYSE SPATZ CAPLAN, MA:**

If anyone has any other comments, if you'll raise your hand, I'll give you the microphone.

[Miscellaneous conversation]

**WOMAN:**

Also, navigating the communication between teams of doctors.

**KATHRYN NOBLE, MSW, LCSW:**

Okay.

**WOMAN:**

That's a nightmare.

**KATHRYN NOBLE, MSW, LCSW:**

Okay. Well, those are all really, really good points — we'll touch on all of those.

The first thing that we can talk about, as far as patient navigating is concerned, is we'll talk about what a patient navigator is. ... A patient navigator is that person who can help you ... organize everything you need to organize [following] ... a diagnosis of cancer, [or if] you suspect that you have a diagnosis of cancer. [She may help] get your doctors' appointments scheduled, and just really get you through the system. [Without that assistance, all of those tasks, on top of coping with the news of a cancer diagnosis], can be really daunting.

When you find out you have cancer, it's a very, very traumatic event. Then to find out, "Oh, now I've got to make an appointment here, and I've got to go to this doctor's office." In the best health, you don't want to be doing that kind of thing. If everything was going perfectly in your life, you don't want to be trying to figure out doctors' appointments and all those things, let alone in a time of crisis, or in a time of difficulty, when you're dealing with all of the other emotions. Having to deal with this can be really, really difficult.

So, a patient navigator can help you get through all of that, and also overcome a lot of the barriers

that might come along with trying to access care. There can be barriers to care, including financial concerns, language concerns. If you aren't English-speaking, and you're trying to make an appointment, that can be really difficult. You might need someone who can help [connect] you with a translator, or help get you in touch with someone so you can make an appointment. [So a patient navigator helps with] communication, the healthcare system, [assisting with the] ... complexity of the healthcare system, as we just discussed.

Transportation: That's huge. In a city, sometimes it can be a little bit easier with public transportation. If you don't live in the city, or even if you do live in the city [transportation to multiple appointments can be daunting. It can create a financial hardship ... as one tries] to get to treatment. Radiation is every single day, and I think a lot of people, when they find that out, [are frustrated to find out] ... that they have to be somewhere every single day. Even if you have all the money in the world, knowing you have to be somewhere every single day can be very difficult, and [add to that], "Oh, it's going to be \$5 every day." Or even if it's \$1 every day, it still can be a hardship [depending on a person's financial situation].

**WOMAN:**

If insurance doesn't pay for the medication that you're taking, such as Arimidex or something like that, do[es the oncology social worker] show that road, to ... get Arimidex cheaper?

**KATHRYN NOBLE, MSW, LCSW:**

Patient navigators and oncology social workers are the ... two roles we're going to be talking about here. Both of them can help you, but they do different things. I'm an oncology social worker. So as an oncology social worker, I would absolutely help someone access medications. We will go over that a little bit later. But there are certain things that we would do to try to make sure that someone has their medications. It can be very difficult at times, but that is part of our responsibility: to make sure that someone [has access to] all of their treatment [and that their treatment isn't hindered by financial issues]. So medication is definitely something that I would be concerned with.

**WOMAN:**

... You talked about language, culture and communication. Occasionally you'll find someone who's deaf — I mean totally unable to speak at all, so you have to have someone special for that.



**ELYSE SPATZ CAPLAN, MA:**

Someone who knows sign language; someone who can communicate. That would be an interpreter.

**KATHRYN NOBLE, MSW, LCSW:**

Right.

**ELYSE SPATZ CAPLAN, MA:**

Whether it's a different language, such as Spanish or any other language, it's the same for people who are hard of hearing, [or] hearing impaired, where they need an interpreter who can do sign language — good point.

**KATHRYN NOBLE, MSW, LCSW:**

So, when you're thinking of a patient navigator, you're really thinking of someone who, when they navigate you through the system, they're helping you get through all of these barriers. [Those barriers] may include [needing] a translator, [or] just getting you to the right place so that you can get your treatment, so [the experience as a whole is] as low-stress as possible.

**WOMAN:**

Where do you find a patient navigator?

**KATHRYN NOBLE, MSW, LCSW:**

Where do you find a patient navigator? Not all places have a patient navigator. So we are going to talk a little bit about that now.

The American Cancer Society actually has a patient navigator program. [For more information about the American Cancer Society Patient Navigator Program, call (800) 227-2345]. So [the ACS does] not have a patient navigator in every hospital, [but] it is a nationwide program. Jefferson actually does have a patient navigator. . . .

**WOMAN:**

Is there a social worker in every hospital?

**KATHRYN NOBLE, MSW, LCSW:**

Usually. [But a more specific question is]: Is there an oncology social worker in every hospital? Most cancer centers across the country do have a social worker. . . . [But] there are ways to locate an oncology social worker. AOSW, the Association of Oncology Social Workers [<http://www.aosw.org/html/prof-links.php>], has a directory on their Web site. So if you [speak with] your doctor, [or to other healthcare professionals at] your hospital and say, "I need to speak with an oncology social worker, I need to speak with a social worker." And they say, "We don't have any here." . . . then you can go ahead

and look for someone there.

Also, if you talk with the hospital case-management staff, there's usually a social worker in the hospital, at the very least in the inpatient units. They might be able to refer you to an outpatient social worker, to try to get that assistance.

**WOMAN:**

Does the American Cancer Society [also refer to oncology social workers]?

**KATHRYN NOBLE, MSW, LCSW:**

. . . I'm not exactly sure about that, but they might be able to point you in the right direction.

So, the other help — the American Cancer Society has patient navigators. But the actual term, "patient navigation," and the concept of patient navigation, was actually started in 1990 by Dr. Harold Freeman. He started this patient navigation system by taking a group of women [to test whether] it made a difference [to] have them go through the system [with assistance. They received help] . . . getting their appointments and going through the system. So that's really where the patient navigation began.

So, the role of a patient navigator and the role of a social worker, an oncology social worker, overlap in a lot of ways. . . . But in a lot of ways, they're very, very different. A patient navigator provides information on coping with cancer, what to expect during treatment, dealing with side effects. They can refer to support groups, to classes, to counseling. They can help identify resources. They can refer you to medication-assistance programs and different things, home health care, transportation. So they really can act as a middleman between you and the important services that you need. They also are compassionate. They do listen. They do care. And they do help you in that time of need. They also can help you learn to self-navigate the system, so you won't always need to have someone [doing it for you]. They can . . . empower you to . . . do that on your own.

Aside from the American Cancer Society navigators, a lot of hospitals do have care coordinators . . . [also referred to as] patient care coordinator, or breast care coordinator. [That position is set up to accept calls] . . . when you [are] diagnosed, or if you have questions, and they would act as a patient navigator [as well]. They would set up your [standing] appointments, "be at the radiation oncologist on Tuesday," and . . .

act in the role of patient navigator, even though they're not always called the patient navigator. They are essentially navigating you through the system. And they are assessing for various treatments. They are trying to find out if you don't have any insurance, or if you don't have transportation. Often people in those roles will work in tandem with an oncology social worker. . . .

**WOMAN:**

Are they the ones, also, that . . . break down what the doctor's telling you, and [communicate in] . . . layman's words —

**KATHRYN NOBLE, MSW, LCSW:**

You're asking if a patient navigator would go with you to a doctor's appointment, and tell you in layman's terms what the doctor —

**WOMAN:**

Right.

**KATHRYN NOBLE, MSW, LCSW:**

Typically, I don't know that to be the case, of someone that would actually accompany you to appointments. I think that —

**WOMAN:**

But the care coordinator that you just spoke of . . . she would do that?

**KATHRYN NOBLE, MSW, LCSW:**

No. Typically they act as a representative from the hospital, help[ing to] coordinate your appointments, and getting you where you need to go, but not necessarily going with you to your appointment[s].

**ELYSE SPATZ CAPLAN, MA:**

But in some instances, Katie, don't you find that some of these care coordinators tend to be nurses or social workers? They may be able to address questions . . . that have come up at your appointments. So while they may not be with you in your appointment — it's actually a role that I played before I started to work at Living Beyond Breast Cancer. I do think they're really good resources for you. If something comes up, and you're not sure, and you don't want to call the doctor, the breast care coordinator might be able to answer your question. . . .

**WOMAN:**

Yeah, because I'm . . . [undergoing my] second bout with cancer. The care coordinator went with me to the doctor, to explain things about my second bout with cancer.



**ELYSE SPATZ CAPLAN, MA:**

Okay. So, I think to sum that part up is you've got to look at everyone on your health provider group as a team. Everyone has a role. And Katie's here telling us the role tonight, specifically, about the patient navigator. But everyone has a role. They're all resources for you. So you may need to ask, more than once sometimes, if you're not getting what you need. Or you may need to ask the care coordinator, "Who's the best person I need to ask this question of?"

**KATHRYN NOBLE, MSW, LCSW:**

Right.

**ELYSE SPATZ CAPLAN, MA:**

But you keep asking your questions.

**WOMAN:**

My experience with the navigator and social worker, they were free of charge. Are they always free of charge to someone?

**KATHRYN NOBLE, MSW, LCSW:**

Typically, if they're associated with the hospital, they're included in your care. I don't know of — well, there may be oncology social workers or social workers that bill your insurance. Sometimes people do that, but more for the counseling aspect. That would be something you would want to . . . ask. I usually make it a point to always tell every patient, "All of my services are included in your care," up front. That way they don't wonder if they're going to be billed or — right.

That's a really good question about [whether] someone would accompany you, because you may have had an experience where someone did. I think it is really dependent on who your team is, and what their roles are. Sometimes I may be in a position where I'm in the clinic, and the doctor is going to be talking to the patient, and they might say, "Katie, can you come in here?" I'll be in the room, and I will be there to listen and to help.

[Speaking simultaneously]

**WOMAN:**

The words that the doctors use can scare you half to death.

**KATHRYN NOBLE, MSW, LCSW:**

Right, right. And . . . even if we can't be there with you in the office, we are there to answer questions. But we can also give you tips beforehand to make that easier. One thing is [to] try to bring someone with you. Always try to bring someone with you, because your brain is going fast, and you're trying to process it, and you're not hearing

half of the things that they're trying to tell you. That other person can sometimes get a lot of that information. I had one patient tell me that the doctor said "cancer," and after that, he said, he just saw his mouth moving, but he didn't hear anything coming out. [Laughter]

So, also, there's another thing that we usually recommend, and that's getting a notebook. Get a notebook, and bring it to every appointment. Write questions down while you're driving home — well, not while you're driving, but whenever you can — just go ahead and write down those questions. Because if you just walk into the doctor's office, you're not going to remember everything you wanted to ask. Then you're going to turn around and walk out of there, and you're going to think of ten questions that you meant to ask.

**WOMAN:**

And have your support. . . A friend of mine, I'm helping her. I'm her support system. She [asks me things such as], "If I don't remember, can you, you know, say it to the doctor," because she's scared.

**KATHRYN NOBLE, MSW, LCSW:**

Okay.

**WOMAN:**

Usually, I'm the one that's answering a lot of questions, with a couple of [her comments] . . . on the side.

**KATHRYN NOBLE, MSW, LCSW:**

Okay. So, yes, it is great to have a representative, or to have support, and [to] have things written down.

One tip: If you're going to write down your questions, keep a notebook so that everything's in the same place. But if you're writing down your questions — and this is really a tip for talking with your doctor, because it can be very difficult to talk with a doctor. Most of us don't know how to communicate with doctors. . . Doctors are scientists, really. Some of them have a great bedside manner, and some of them, not so much. . . They see the cancer and say, "Oh, there's a person around this cancer." And we have to remember that they are worried about treating your cancer. So we're glad that that's their focus, but we also want to try to get the most out of our time with them, so that we can get the information that we need.

So, one thing I [advise people to do is] . . . when you have your questions, write them down. Then, when you're in there with the doctor, if you say, "Doctor, I have some questions," they might

be [thinking], "Oh, my gosh, am I going to be here for the rest of the day?" They're thinking, "I have 20 more patients after you." So you say, "Doctor, I have some questions." Instead of saying, "I have some questions," say, "Doctor, I have five questions here." So then they all of a sudden say, "Okay. There's a beginning and there's an end." [Laughter] Then, if you say, "I have five questions. It's going to take about five minutes," or, "It's going to take about 10 minutes," then they're [probably thinking], "Okay. I know how long I'm going to be in here. I know which questions I'm going to ask."

. . . [In your notebook], underneath your questions where you're writing, leave a space. That way, when they're answering your question, you can write it down, so when you're [pondering their answers] the next day, or [that evening and you think], "Well, what did he say about this?" you can reference it, and then you can remember what the [doctor said], because you're not going to remember everything.

**WOMAN:**

. . . When I go to the doctor, I write my questions down, but I take a tape recorder with me, and I tell them that I have a tape recorder with me. Is it okay? It helps me so much. I'm finally a little bit more relaxed to hear it back and say, "Oh, that's what he meant."

**KATHRYN NOBLE, MSW, LCSW:**

Great.

**WOMAN:**

Just a thought.

**KATHRYN NOBLE, MSW, LCSW:**

That's a great idea. And if they will let you do that, I do recommend that, because then you will — if you're writing it down, you may not get all of the information. Sometimes you have to ask your doctor if this is okay, because not everybody will want you to do this. I'm not saying that it's okay, but you might want to write down your questions and then fax it to them, or give that to them, and tell them they can get it back to you in a little bit. That way, when they have a free minute, they can sit down, and write the answers and get it back to you. So it's not like they're rushed. Not everyone would do that, but that might be [another option for getting] . . . the information that you need.

. . . You have to be a little bit clever, and learn new techniques that you may not have used before. Typically, if you're going to the doctor for a sore throat, and he tells you what to do and you forget



half of it, well, it's not really going to be that big of a deal, maybe. But it's very important with cancer treatment to make sure that you have a good understanding of all the different parts of [your care plan].

So, we talked about [what] patient navigation [is], and what a patient navigator is. Now we're going to talk about an oncology social worker. I'm a little biased, because that's what I happen to be. But oncology social workers are really the primary providers of psychosocial services in cancer centers, all across the world. So if you go to cancer treatment in Australia, you'll hopefully find an oncology social worker there.

But it's not only because of our knowledge about the psychosocial impact of cancer, but also of our versatility. Social workers . . . are found [assisting with various types of care]. So while we are licensed counselors, we are not typically [seeing you only in an appointment-type setting] — and while we can be in the office for a 50-minute hour, we are often in the places where you go: we're in schools; we're in hospitals; we're in doctors' offices. We're out there. So you [can] come to me and talk about symptoms of depression, but I can also help you find a resource to pay your electric bill. So we really are looking at the whole picture. We really are looking at Maslow's Hierarchy of Needs — if you aren't able to pay your electric bill or eat that day, you're not really going to be able to process the body image issues, or [any other] difficult [issues that were revealed to you at your appointment], because you're really worried about the immediate needs. That's what we try to [do], make sure we can cover everything.

Your oncology social workers are master's level social workers. Most of us are licensed clinical social workers. We are a member of your interdisciplinary team. So we're a team member, like your doctor, and your nurse and your physical therapist. I often say that people go to the doctor, they go to the oncologist, and they don't expect to see a social worker there. I've had people say, "Oh, I don't need welfare." Well, that's not really what I do. That's good, because I don't think I can get you that anyway right now, that is not my role. My role is to help you adjust to this illness in whatever way you need help adjusting.

**WOMAN:**

Can [oncology social workers] answer medical questions?

**KATHRYN NOBLE, MSW, LCSW:**

Can we answer medical questions? No. We do not talk about any of the medical side, even though some of us may have garnered some medical knowledge in the time. We don't do that. We would refer you back to your physician. Sometimes, I can even do things like, "Oh, I forgot to ask the doctor this." And I say, "Well, you know what? Hold on a second. Let me go run and get Dr. so-and-so and get him back here," or, "Let me go ask him real quick for you," anything that I can do to make it easier. But I'm not going to answer any medical questions, because that's not my area of expertise.

Social work has been in the hospital [setting for] quite a while, since 1919. The first social worker in a hospital was Ida Canon at Massachusetts General in [the 1910s]. So we have been a part of your treatment team for quite a while. And we have a very large role. We can help you access information. We can help you consider decisions about treatment; understand Social Security and Medicaid and Medicare; apply for financial assistance. . . . The role of the oncology social worker also depends on the facility where you're being treated. Sometimes they do more case management; sometimes they do more counseling. But you can always go to [her or him] and ask, "Where can I get this help?" So even if they don't do it, they will refer you, or they should refer you to someone who will.

We can also teach you about talking with your treatment team; talking with your children; talking with your family, friends; coping with your emotions; reducing stress; how cancer affects sex and intimacy and fertility and feeling good about your body; complementary and alternative medicine; clinical trials; life as a cancer survivor; past diagnosis; planning for your care with advanced directives [<http://www.cancer.gov/cancertopics/factsheet/support/advance-directives>] — that's one thing we do a lot, talking about advanced directives, living will, power of attorney. We can also help you access different types of care, referral for help at home. [We can refer you to ways to get various at-home tools for your care, such as a] walker, if you need a hospital bed, if you need tube feedings. If you need any of those things, it can be really difficult to figure out how to even get that. So if we need a doctor's order, we can obtain a doctor's order. We can fax it to the company. We can have the walker delivered to your house — all of those things so that you don't have to worry about that.

You may come to me and ask for a walker, and I might say, "Well, your insurance isn't going to cover a walker," which may be the case. I'm not going to promise you that your oncology social worker . . . [is] going to be able to get everything that you [request]. But we can definitely talk about it, and definitely, definitely try.

Some of the challenges of a cancer diagnosis — I do want to go through the points that we had talked about before — would be trouble adjusting to the illness, family and social isolation, family conflict, financial concerns, transportation concerns — that can often be a really big one — treatment decisions, concern about quality of life is also a big one, problems adjusting to changes in care, and also problems communicating, grief problems, end-of-life issues, cultural concerns, and caregiver support.

So . . . in the beginning some people had talked about different things that they were interested in discussing. We went over communication with your doctor. . . . Also, wigs: I heard wigs as something that can be important to you. Has anyone been able — has everyone been able to access a wig, or has that been an issue for anyone? A wig? The American Cancer Society . . . can help link you with wigs. Also, I know at Jefferson, we do have patient services can get you a wig [<http://www.jeffersonhospital.org/patient/article3954.html>]. And that would be something that you would want to talk to your social worker or your oncologist about, because we can access that for you.

**WOMAN:**

This is direct[ed] to someone who might need it. . . . I don't have the thing, but "Look Good...Feel Better," do you know when that's occurring and where?

**KATHRYN NOBLE, MSW, LCSW:**

Yes. "Look Good...Feel Better" [<http://www.lookgoodfeelbetter.org>], that's a great segue into the "Look Good...Feel Better" program. . . . "Look Good...Feel Better" is a program by the American Cancer Society, and it's held at a variety of hospitals across the country. It's a program for women going through cancer treatment. They give you makeup, all donated from Clinique and Estee Lauder, and all this fancy makeup. We have a cosmetologist come in from the community, who's been trained by American Cancer Society. [He or she] goes through the steps of application of the



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makeup ... [does] wig-styling, and shows tricks with scarves and turbans. It's a great program. I've been facilitating it for a long time. ... It's usually a little — one of the [lighter], happier things that you might do during treatment.

### **ELYSE SPATZ CAPLAN, MA:**

And it can feel like a support group. You may meet other women going through treatment, who are sharing some similar challenges or difficulties. In my former job, where I was at [Albert] Einstein Cancer Center, I also facilitated a "Look Good...Feel Better." They were just a bright spot in all of our days, because it is a lighter-type program.

... Getting vital information that will affect your appearance affects the way you think and feel about yourself. [While you're doing that], you're also meeting other women [who] may become your buddies or your friends. You may exchange phone numbers, and you may get together with them.

So it's a nice support network, without it being a traditional support group. You can really learn, as Katie said, amazing tips that can [help you] deal with your complexion. ... I went through the program 18 years ago when I was going through chemotherapy. My complexion was not what it had been. They gave me a foundation-base that completely changed my natural skin tone, so I could use my regular makeup, as usual. It was like magic. So there [is] lots of magic that the cosmetologists can — and then you get a goodie bag, as Katie said, with lots of makeup to try and fragrances. So definitely check it out.

### **WOMAN:**

Eyebrows, how to get it.

### **KATHRYN NOBLE, MSW, LCSW:**

They do. They teach you tricks with eyebrows and —

### **ELYSE SPATZ CAPLAN, MA:**

Mm-hmm.

### **WOMAN:**

[Inaudible] ... natural. It's amazing. ...

### **ELYSE SPATZ CAPLAN, MA:**

... I guess the bottom line [is] if you — depending on where you live or work — if you call the American Cancer Society office that's near your home, you may be able to find locations that are convenient for you.

### **WOMAN:**

[Inaudible]

### **KATHRYN NOBLE, MSW, LCSW:**

[The] American Cancer Society would be the place to —

### **WOMAN:**

[Inaudible]

### **KATHRYN NOBLE, MSW, LCSW:**

They can give you all of the area "Look Good...Feel Better" [sites]. If you just missed one, chances are there's one in the next few weeks —

### **ELYSE SPATZ CAPLAN, MA:**

Monthly.

### **KATHRYN NOBLE, MSW, LCSW:**

— for you to attend.

So, I did list some resources here. It's in your packet. Obviously this is not an exhaustive list by any stretch. ... The American Cancer Society [<http://www.cancer.org>] [has their] ... wig program, [as I mentioned earlier]. The American Cancer Society, it depends on where you're located. If you live in New Jersey, the resources there are different than here. So you would want to call them, or you would want to ask your oncology social worker or your patient navigator for information about the American Cancer Society. Then they can tell you what their programs are, and what they can assist with.

CancerCare [<http://www.cancercare.org>] is a great organization. It's in New York. I use it on probably a daily basis. They do financial assistance, and they have support groups, they have telephone support groups. They also have a co-pay assistance program. It's very specific. The diagnoses are very specific. But if you do qualify, they will pay for your co-pay. So that's a — and, again, you would want to call CancerCare to find out exactly what they can help with, or talk to your social worker [and have him or her call CancerCare].

The Healthy Woman Program [through the Pennsylvania Department of Health], [[http://www.portal.state.pa.us/portal/server.pt/community/healthy\\_women/14172/healthywom\\_an\\_program\\_home/557855](http://www.portal.state.pa.us/portal/server.pt/community/healthy_women/14172/healthywom_an_program_home/557855)], does breast and cervical screenings. [For more information, call (877) PA HEALTH (724-3258).]

The Leukemia and Lymphoma Society [<http://www.lls.org>] is another great organization. They help with blood cancers, and they can help with medications and co-pays and different financial resources. But you would want to contact them to find out exactly what they offer.

Living Beyond Breast Cancer is a great organization, and they have a [Cis B. Golder] Quality of Life grant. [Editor's Note: This grant is available to women in the eight-county Pennsylvania and South Jersey area. For information: [http://www.lbbc.org/content/event/cis-b-golder-quality-of-life-grant.asp?section\\_tag=G](http://www.lbbc.org/content/event/cis-b-golder-quality-of-life-grant.asp?section_tag=G)] You'd want to contact them for the eligibility and for the information about that. And also, if you go to your oncology social worker, they can make that referral for you.

The National Association for the Terminally Ill [<http://www.healthfinder.gov/orgs/HR3440.htm>], or call (866) 668-1724 [offers] financial assistance for families of someone who's terminally ill.

NeedyMeds [<http://www.needy meds.org>] is probably my favorite [service] in the world, and is one of my favorite things to talk about. Is anyone [working] with NeedyMeds? NeedyMeds is actually a Web site that has every single medication. The pharmaceutical companies have programs to help you get your medication, if you don't have coverage for that medication. It doesn't always help with co-pays, not necessarily that. But if you don't have prescription-coverage, and you can't afford that medication, then the pharmaceutical companies will typically get you that medication, or do something. Yes?

### **WOMAN:**

In trying to find a patient assistance program for medication, I found that if you have any prescription coverage, most of the time they will not [provide assistance]. Is there a Web site or something, for future reference, that would thread out those that do not mind if you have some prescription coverage, so that you can do patient assistance? As long as we have patent laws that allow them to just drain money out of us, it's really difficult, [financially], to keep up on some medications. It's really a problem. My last [medication cost] was devastating. So, is there a way to thread out those who are going to put a door between you and medication, simply because you do have prescription coverage, [but still have trouble paying what that coverage does not pay]?

### **KATHRYN NOBLE, MSW, LCSW:**

Well, that's a very good question. It's a very difficult system, and you have to look at a couple of things. First you're looking at co-pay assistance versus medication assistance, prescription assistance. And, yes, often, if you do have some



coverage, then a lot of the drug companies will not cover the co-pay. That's where you're dealing with a co-pay.

**WOMAN:**

[Inaudible]

**KATHRYN NOBLE, MSW, LCSW:**

The pharmaceutical company, that they won't — you're saying that they won't. And that really does vary by pharmaceutical company as well. So, the first thing I would recommend is actually get with your social worker or your doctor about this situation. And actually —

**WOMAN:**

[Inaudible]

**KATHRYN NOBLE, MSW, LCSW:**

PACE [in Pennsylvania, <https://pacecares.fhsc.com>]:

**WOMAN:**

You have a co-payment, but it will be much lower with this PACE.

**KATHRYN NOBLE, MSW, LCSW:**

PACE?

**WOMAN:**

Yes. They make the co-payment. It's still a co-payment, but it's much lower.

**KATHRYN NOBLE, MSW, LCSW:**

I'm not actually —  
[Speaking simultaneously]

**WOMAN:**

...My sister was getting a medication called Arimidex, and she was paying [more than] \$100 ... for it. Through [this program], she only pays [about] \$9 for the co-payment.

**ELYSE SPATZ CAPLAN, MA:**

I think what you're raising is — and we don't have all the answers because of the fact [that] it's very complex. As Katie was saying, every pharmaceutical company has [its] own patient assistance program. They all have their guidelines and parameters and things like that. And you need to apply [to find out if you are eligible].

So, as Katie was saying, you really need to enlist your doctor. We need to be up-front with our doctors, and say what hardships we have. So if paying for your medication, [or] for your cancer treatment or for any care that you're receiving is a hardship — because you either don't have a prescription plan, the co-pays are too burdensome, or for any other reason — we really need to

disclose that [information] to our doctors. We really need to say, "This is really hard for me. What help might I have?"

Then, whether they do it, or they empower the nurse or the social worker to help, I think the bottom line in our message tonight is there are patient assistance programs. They're all different. There are resources, but we need to be up-front and say what's hard for us, so that any application process can commence, and we can work through it. These ongoing treatments, as you referenced — [such as] Arimidex, a hormonal therapy that many women take for five years. We hear [about this challenge a lot] in the Living Beyond Breast Cancer office. It is very hard for a lot of people. But companies that make these medicines do have programs. It's just [that] we need to [persist], to ask the questions and let our doctors know, and not feel ashamed or embarrassed that this is a hardship.

**KATHRYN NOBLE, MSW, LCSW:**

Right.

**WOMAN:**

We need to learn be our own advocate.

**KATHRYN NOBLE, MSW, LCSW:**

And we can — oh.

**WOMAN:**

PACE is an organization that you can apply for. You don't have to go through your doctor or nurse. You speak with, I think it's PCA [Philadelphia Corporation for Aging, [http://www.pccares.org/News\\_List.aspx?newsID=800M58B15K30&orgID=763P7J24J26](http://www.pccares.org/News_List.aspx?newsID=800M58B15K30&orgID=763P7J24J26)], and you can be interviewed and fill forms. And it's open to anyone who wants to apply for it.

**KATHRYN NOBLE, MSW, LCSW:**

That's good to know.  
[Speaking simultaneously]

**WOMAN:**

[Inaudible] ... organization.

**ELYSE SPATZ CAPLAN, MA:**

We're familiar with the organization, but —  
[Speaking simultaneously]

**WOMAN:**

[Inaudible]

**WOMAN:**

It's for — usually I think it does — low income. Yeah. Uh-huh.

**ELYSE SPATZ CAPLAN, MA:**

So it's just one more resource for all of you to look into. Thank you.

**WOMAN:**

[Inaudible] ... I was just asking for a repetition of the question and the answer. I'm sorry. Just repeat that, please, what you just said.

**ELYSE SPATZ CAPLAN, MA:**

She was ... trying to tell us ... what PACE is. And it's a local resource.

**WOMAN:**

[Inaudible]

**ELYSE SPATZ CAPLAN, MA:**

... The Pennsylvania Corporation for Aging may give you access to more information about the PACE program, right.

**KATHRYN NOBLE, MSW, LCSW:**

If you get to an oncology social worker or to a social worker, and you ask them for information on resources, often we will refer you to an organization like PCA. Then you will get to someone there, and they may refer you out to some other organization. I don't know of everything ... we try to find out everything we can. We try to get as much information for you as possible. But there's just no way I could know everything that exists. So I may be able to refer you out to someone else who can find that resource for you.

**WOMAN:**

Okay. AstraZeneca — you've heard of that — they will help you on an individual basis for your medication [<http://www.astrazeneca-us.com/help-affording-your-medicines>]. They'll send it right to your home, as long as your doctor provides the prescription.

**WOMAN:**

[Inaudible]

**ELYSE SPATZ CAPLAN, MA:**

You need to fill out an application. But that's all the companies [tend to require]. And that's where the NeedyMeds —

**WOMAN:**

But they're really helpful, AstraZeneca.

**KATHRYN NOBLE, MSW, LCSW:**

Let's go back to NeedyMeds for one second. The NeedyMeds Web site is a database [of] pretty much of every single pharmaceutical company. You can check by pharmaceutical company. You can check by prescription name, by drug name. So



if you're looking for Arimidex, you click on A, you go to Arimidex, you click on it, and it will tell you exactly what the drug company's programs are, [and whether] you can download the application online. I know that one of the companies, Bristol-Myers [Squibb; <http://www.bms.com/products/Pages/programs.aspx>], I believe, one of them we have to actually — you have to have someone from the hospital ... [provide] an advocate number. We have to call. And then we can give you a coupon, right there in the office, to bring to the pharmacy and get your medication. So they are all very, very, very different.

**WOMAN:**

[Inaudible]

**KATHRYN NOBLE, MSW, LCSW:**

Most of them do go by your income, yes. And if you don't qualify for something, sometimes it's really — and sometimes people don't like us for this, but sometimes it really is a matter of looking at maybe money-management skills. Or maybe we need to reduce these bills, so that we can afford these bills. Maybe not everything is going to be covered. I have had patients who have [withdrawn from] ... their retirement-accounts to pay for co-pays for meds, because they cannot get assistance. [The fact that they have] a lot of money in the bank, [keeps them from qualifying for assistance, even if that money is intended for retirement]. That's really just a sad reality of the state of health care. There's nothing we can do about that. I know sometimes that's very frustrating, because we want to find assistance. We want to find help, so that it doesn't make our lives more difficult. But things like that — they did, they had to deplete a lot of their retirement to pay for their medications.

**WOMAN:**

[Inaudible]

**WOMAN:**

... [A backup plan for patients that] ... my doctor just adopted, when I was first diagnosed [the office gave away free samples of medicine]. The first thing [my doctor's office asked me is whether I had] ... a prescription plan. If I didn't, they had samples. They used to keep a stockpile, and that's who — they would give it to people who didn't have [coverage for] prescriptions. ...

**KATHRYN NOBLE, MSW, LCSW:**

Sometimes they will do that. There are different plans, like a reimbursement, where [doctors] will give [patients] the med, and then

the drug company will reimburse the[ir office]. So there are a lot of different ways that they can do that. And yes, you do want to be up-front with your physicians.

If you do have a prescription plan, and it's a matter of a co-pay, you're usually dealing with a different — you would still want to see what the company offers, but you're usually dealing with something else. ... CancerCare has a co-pay assistance program. The Patient Advocate Foundation [<http://www.patientadvocate.org>], is another good resource to check with]. You would want to discuss it with one of us, but there are some co-pay assistance programs out there. We would try to help with that. There are a lot of agencies and organizations that might be able to help. ... We can even find financial grants out there sometimes.

... I often tell people, "Print out the \$4 list from Wal-Mart or from Kmart. Print it out, and then bring that with you to your doctor." So if they're prescribing stuff, say, "Anything off this list, if you can prescribe this first, do it." Now, sometimes they can't, of course. But if they say, "Well, you know what? This will work. I can give you this instead of this," I tell everyone that. Just bring that list with them and say, "You give me anything off this list," even if you have drug coverage. What's your co-pay going to be, \$25? That's \$4. So try to get everything — and even with your general physician. ...

**WOMAN:**

I just want to ask a question about NeedyMeds, the Web site, and their products. Is NeedyMeds medication for all symptoms of other illnesses, or is it just for cancer?

**KATHRYN NOBLE, MSW, LCSW:**

NeedyMeds is actually just like a clearinghouse of different medications, all medications. So it's every medication. Some of them, you might click on it, and it might say, "there's no information," or, "there's no program for this medication." But, typically there's enough on there to help [you find what you need]. ...

**WOMAN:**

Some of the generic medications that I take, the doctor writes for three months rather than for one month [and that saves me some money].

**KATHRYN NOBLE, MSW, LCSW:**

\$10, right?

**WOMAN:**

[When I get a three-month prescription all at once], I only have one co-pay instead of three.

**KATHRYN NOBLE, MSW, LCSW:**

Yeah, oh yeah. That's true. That's true.

**ELYSE SPATZ CAPLAN, MA:**

See, and that's a great point. Some insurance companies will only pay for a one-month supply. That's what makes everything so complicated. But if you have an insurance plan [that allows for a longer duration], and you can get more than one month, by all means, that's great.

**KATHRYN NOBLE, MSW, LCSW:**

So we're going to go ahead and open it up now to questions and answers, which we've kind of been doing.

**ELYSE SPATZ CAPLAN, MA:**

Well, I just want to say thank you, first. We'll just sort of transition, and [offer] thank[s to] Katie for a great presentation. [Applause]

**KATHRYN NOBLE, MSW, LCSW:**

Thank you.

**ELYSE SPATZ CAPLAN, MA:**

[We'll transition now into the question-and-answer session] on patient navigation. [I am sure there are] lots of burning questions and comments here. ... I'd like to try to get around to as many different people [as possible], or those of you who may not have had the chance to make a comment, or ask a question, please feel free to do so.

**WOMAN:**

I don't have a question. I have a comment. I'm going on five years [as a] breast cancer survivor. I feel safe to say that I am cancer-free. In addition to that, I'd like to thank this lady here, because I had all my treatment at the Kimmel Cancer Center. And along my journey, I am happy ... to say that I really didn't have any problems. My technicians, my doctors, my oncologists, my radiation doctors were [all] very nice to me. I had a wonderful journey.

I have a testimony, and I just want to, on behalf of Jefferson, Dr. Ronald Cantor, if you know him or not, the infamous Melvin Moses, [MD] — very, very professional people. ... I had a journey, but it was a wonderful journey along the way. I want to ... ask you to tell your doctors, and everybody on your team, to please keep up the good work. Thank you so much.



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## **KATHRYN NOBLE, MSW, LCSW:**

Thank you. [Applause] Thank you.

## **WOMAN:**

I have a question concerning — I know with all this healthcare stuff going around, do you guys get a chance to advocate for some of the concerns of cancer patients with the politicians? Or is that something that has to be done individually?

## **KATHRYN NOBLE, MSW, LCSW:**

That's a good question. I think that that is done often in healthcare groups. There are groups of social workers, or groups of professionals, that would lobby for things and that do promote — it just depends on I think what someone's . . . role is. I know, on a daily basis, I'm not actually working for advocacy in that part. But I think it would vary [according to each person's role].

## **ELYSE SPATZ CAPLAN, MA:**

I think a lot of the nonprofit organizations, like Living Beyond Breast Cancer, and some of the other nonprofit organizations, are taking on advocacy or [other] issues of importance [to you]. So you can feel free to reach out to other groups in addition to your hospital-based team, if you've got issues that are burning or are important to you.

## **WOMAN:**

Hi. I'm actually a public health educator by profession, [and have been] for about 20-plus years — a . . . profession [closely related] to social work. A friend of mine by the name of Janet Cash, who's director — I'm sure some folks in here. Yes. Well, I know for a fact she receives [support] from Living Beyond Breast Cancer for her breast cancer support group, known as Sisters Health Initiative. So I'm sort of representing her. I didn't tell her that, but I try to come down to these events, mainly to keep informed and updated with information pertaining to breast cancer and other health issues, as a public health educator. So if anyone is interested in joining her group, you can just give me your information afterward. I can pass it along to her, and she can send you information on the meetings. They meet every third Saturday of the month at St. Joseph's Hospital in . . . North Philadelphia. . .

## **WOMAN:**

First of all, I'd like to thank you. I think your information is very interesting and important. [Applause]

## **KATHRYN NOBLE, MSW, LCSW:**

Thank you.

## **WOMAN:**

I wish I'd had an oncology social worker on my team when I was diagnosed. . . . There are a couple of questions I left for Jefferson social workers, [who] run the public programs. But — let's see. What was my question? I'm sorry.

## **ELYSE SPATZ CAPLAN, MA:**

It's lost. It'll come back. It'll come back.

## **WOMAN:**

So, my question is: I know that a lot of breast cancer patients, they probably have the option of quitting their work or just staying home and healing. [In] my situation, I carry the insurance . . . for my family — for my husband and my daughter. So I don't really have a whole lot of options [for] not working. Sometimes I have to keep working, keep working to get the insurance under me. So if I lose my job or [quit working], then I won't have insurance. I'm having difficulty finding resources for somebody in my situation, who has to continue working because I have family covered under m[y] insurance plan]. I know there's Medicare and all that stuff, but that's further down the line. So it's just hard for me to find resources for myself in that situation.

## **KATHRYN NOBLE, MSW, LCSW:**

So, by resources, are you asking about an alternative to the insurance coverage by your [employer]?

[Speaking simultaneously]

## **WOMAN:**

[Yes], by my employer, if I decide to quit. Right now I'm on short-term disability, but I can only go so far. At some point, I'll lose my job. What do I do at that point?

## **KATHRYN NOBLE, MSW, LCSW:**

You do have the option of COBRA [Consolidated Omnibus Budget Reconciliation Act] after —

## **WOMAN:**

Yeah, which is —

## **KATHRYN NOBLE, MSW, LCSW:**

— which is very expensive.

## **WOMAN:**

Expensive, right.

## **KATHRYN NOBLE, MSW, LCSW:**

And you can also purchase—you can always purchase insurance if you have no break in coverage. Now, you would want to definitely discuss this with an insurance company and

find out what your options are. They will [allow you to enroll, and sell you] . . . a policy if you don't have any break in coverage. But it typically is expensive, like COBRA [[http://www.cobrainsurance.com/know\\_your\\_cobra.htm](http://www.cobrainsurance.com/know_your_cobra.htm)]. It's not going to be a very affordable policy, especially if you're not working. Often our insurances are cheaper when we're working, because they're supplemented by our employer.

## **WOMAN:**

And that would cover her and her whole family?

## **KATHRYN NOBLE, MSW, LCSW:**

If she did get a policy like that. You would have to look into the options. That's one — because of the situation that our society is in, where we don't have any type of universal health coverage, where we don't have those things, there aren't a lot of options. And that is frustrating. That is good that you have the short-term disability for now. . . . What happens is typically people go on COBRA. If they do stop working, and they do lose their insurance, typically COBRA is the next step. COBRA is limited. And then at that point, there's Medicaid [<http://www.cms.hhs.gov/home/medicaid.asp>] as an option, and there's also . . . other private insurance [plans] out there. [Editor's Note: For additional information on insurance coverage, go to <http://www.coverageforall.org> or visit this American Cancer Society link

[http://www.cancer.org/docroot/MLT/content/MLT\\_Ix\\_Medical\\_Insurance\\_and\\_Financial\\_Assistance\\_for\\_the\\_Cancer\\_Patient.asp](http://www.cancer.org/docroot/MLT/content/MLT_Ix_Medical_Insurance_and_Financial_Assistance_for_the_Cancer_Patient.asp)].

## **WOMAN:**

[Inaudible]

## **KATHRYN NOBLE, MSW, LCSW:**

I wish I had some secret in my back pocket, some secret resources. With any luck, things will change, and it won't always be [so challenging to find affordable health insurance resources].

## **WOMAN:**

. . . My doctor [was] . . . very open. They directed me to a social worker. But I belong to many support groups, and many people are not [given that kind of guidance]. . . . They're totally confused, just diagnosed [with breast cancer, and after that] no one tells them where to go. It ends up the support group tells them [to] go to the social worker. Who should be telling — shouldn't the doctors be telling people this or —



**KATHRYN NOBLE, MSW, LCSW:**

That's like an endless battle for my position. We try everything we can. We put forms in everyone's paperwork. We put bulletin boards up. We make marketing materials. We talk to the physicians. We try to meet new patients as they come in. Still, I get people saying, "I wish I knew you were here a year ago." [And from my position], it's like, "Well, I don't know what else I can do."

So it is a matter of —

**WOMAN:**

[Inaudible]

**KATHRYN NOBLE, MSW, LCSW:**

... We try everything on our end to make it so that people know from the very beginning that we're there, because a lot of the times that's when they need us — in the beginning. They may need us five months later, but they might need us on the first day, too.

So there are [programs] at Jefferson [that I know about, that I can refer people to]. We have multidisciplinary clinics. If someone was coming in with, let's say, a brain tumor, they would see the surgeon, the medical oncologist, [and the] radiation oncologist, all in one day in the appointment. I would come in, and I would see all of the new patients on that day. So not only are they seeing the physicians, but they're seeing the oncology social worker, too. Right up front I can say, "These are what the resources are. This is how we can help."

**ELYSE SPATZ CAPLAN, MA:**

I'm going to get a comment here, but I also want to say a lot of doctors don't know what the health insurance situation is for their patients. There are other people in the office who take care of your health insurance. The doctors don't always see on your chart. What they're looking at is: What was your blood work that was just run? What was your weight? Did you report any symptoms to the nurse, or the fellow, or the resident, or whoever might have seen you before they got in? That's what they're looking at. They're looking at what's in front of them, and they're interested to know how you're feeling that day. But they're really not always aware of your insurance situation.

So, again, it's an instance where you need to bring it up. It is. But there are other people, like Katie said, the social workers and other members of the office staff, [who] might be responsible for helping with health insurance.

**WOMAN:**

This is just a comment for the lady — well, she's gone. But, for those of us who work, and who have to work, another resource might be the human resources department wherever you work. Let them know — they know you're ill. But I know that there are instances where individuals will give up their sick time, or some vacation hours, to extend your ability to stay with your job along the way. So that's something that your own coworkers might be willing to do to help someone who's [ill, and is running out of options].

[Speaking simultaneously]

**KATHRYN NOBLE, MSW, LCSW:**

That's a very, very good point. That's a very good point. Also, asking your employer if maybe you can telecommute, maybe you can work from home, maybe you can work on a reduced schedule. I had one patient who, his boss said, "You know, you worked enough overtime over the past 15 years." He said, "Don't worry about it. Just take all the time you [need]" — not everybody's going to be like that. But I think it is important to talk to your human resources, or to talk to your boss, and see if they'll work with you for your schedule and [any other resources you may need.]

**ELYSE SPATZ CAPLAN, MA:**

They're obligated to come up with some reasonable accommodations if you need some accommodations made. They have to at least explore that with you. It may not always be granted, if you need some special accommodations. But if it fits with your work [that you did prior to your diagnosis], that may be possible, too.

**KATHRYN NOBLE, MSW, LCSW:**

Family medical leave, the Family Medical Leave Act, now that doesn't — if you don't have a disability policy with your job, with your employer, the FMLA doesn't give you any money. But what it does do is it holds your job. So that would hold your job for three months, if you need to take some time off. But I know sometimes people will come to me and say, "I want to apply for short-term disability." Well, there isn't a short-term disability. There's only disability, and you have to be disabled for at least 12 months. If you can't tell disability that you're going to be disabled for 12 months, they won't even process it.

But if you think that that's an option, if your doctor has communicated to you that they think that you're going to be disabled for at least 12 months, talk to your social worker, talk to your

doctor, and we will help you apply for Social Security. It may be a matter of me just getting telling you how, or telling you what you might need, or giving you the number. But we would encourage you to do that if that looks like something you might need to do. When you're on Social Security now for two years, then you get Medicare. That comes with it. Now, Social Security doesn't automatically come with insurance, though. There is a waiting period, two years.

And all of my facts — I know this is being recorded, so please double-check it. This is just from my practice. But I always tell everyone, since I don't work for Social Security and I don't work for the drug companies, I do want to make sure that — I'm just kind of giving you some roundabout knowledge from the different areas, but you definitely want to double check with all of the different organizations [and find out about your individual situation, as it applies to these resources].

**WOMAN:**

Could somebody let her know about —

**WOMAN:**

[Inaudible]

**ELYSE SPATZ CAPLAN, MA:**

When you stepped out of the room, the woman back here commented that maybe checking with your human resources department, if the company or business you work for has a human resources department. . . . Some companies . . . may have policies where if coworkers want to donate vacation time or sick time — not all businesses will do that. They're not set up for that. But some might do that. So, the bottom line, which was a really good message, was if you have a human resources department where you work, sit down and talk to them. [Find out] about . . . possible options available to help make this more manageable.

**WOMAN:**

Thank you.

**WOMAN:**

Two things. One is we are now a group of people who have preexisting conditions. So we have to pay attention to what's going on out there. That's number one. Number two: The flu season is at-hand, with all kinds of complications for us. I'm just wondering where to get the best information as to what cancer patients, people in treatment, and cancer survivors should do about the two [flu] shots — [seasonal flu and HINI vaccinations] — or one shot, or whatever that might be.



**KATHRYN NOBLE, MSW, LCSW:**

That is an excellent question for your physician. It's going to depend on where you are as far as your treatment, and where you are individually. . . . If you were to call a general hospital line, they may not know what your situation is. So I would direct that right to your physician.

**ELYSE SPATZ CAPLAN, MA:**

Because everybody may have more than one health issue. Your whole health history is going to help your doctor determine who needs a flu shot, and what series of shots. Or [which shots to avoid], and do you need the pneumonia vaccine on top of that, too — all these other things. So it's great that you raised that as a question, but I think it lends itself to — there's just no one answer for any group of people. It's so personalized and individualized to your health status, other health issues, medications you might be taking, [allergies]. So ask your doctor, and make sure you [bring detailed information about] all the medicines you're [taking], and all the history of your health concerns.

**KATHRYN NOBLE, MSW, LCSW:**

As far as your first question is concerned, you'd want to — when I was saying to make sure you don't have a break in coverage, that's really important when it comes to preexisting conditions. You want to ask, when you talk with an insurance company. Let's say you're going to try to buy an insurance policy outright — you want to mention a HIPAA [Health Insurance Portability and Accountability Act] conversion policy — I'm not really great on this, but you want to explore that with them. Because my understanding is that they would have to provide you with insurance. . . . It's kind of expensive, but if you don't have a break in coverage, I think that's a little bit easier. So that's just some cursory information, but I would definitely check into that.

**ELYSE SPATZ CAPLAN, MA:**

Anyone else with a question, or have we covered most everything for this evening?

**WOMAN:**

Can I ask you to repeat what you just said, going —

**KATHRYN NOBLE, MSW, LCSW:**

The HIPAA-conversion policy? And like I said, I'm not — I don't know a lot of details about that, just enough that you can't have a break in coverage. If you don't have a break in your medical coverage

. . . [and] if you're talking to an insurance company, that you want to ask them about a HIPAA-conversion policy and see what the information [they have on that]. They might say, "That social worker's crazy." But I'm pretty sure that that's going to be a way to help you get a policy. [[http://www.healthhelp.ca.gov/dmhc\\_consumer/hp/hp\\_hipaacp.aspx](http://www.healthhelp.ca.gov/dmhc_consumer/hp/hp_hipaacp.aspx)]

Before I leave, I just wanted to say that we do have some programs coming up at Jefferson that you're all welcome to attend. I have some information up here that you can take. We have a program at Jefferson. It's a Buddy Program [[http://www.jeffersonhospital.org/cancer/article3070.html#buddy\\_program](http://www.jeffersonhospital.org/cancer/article3070.html#buddy_program)]. We will link you up with a survivor who has been through treatment, they've come out the other end and they're trained by us. So we give them support and we — you're not going to get — we try to get more upbeat information, so you're not going to get someone who's miserable, to make you feel worse. The point is that they're going to try to make you feel a little bit better. So we have some information on the Buddy Program. . . . If you are interested in a Buddy, you can call me. And there are other patient programs in the country that I could help you with, too, if we weren't able to accommodate.

**ELYSE SPATZ CAPLAN, MA:**

I was just going to say Living Beyond Breast Cancer has a toll-free Survivors' Helpline (888) 753-LBBC (5222). You can call the toll-free number 24 [hours a day], seven [days a week], leave a message and a volunteer will call back. On Tuesdays, you've got a volunteer in the office that answers the phone from 11 a.m. to 3 p.m. [ET]. At all other times, they'll return the call that day, or within 24 hours. We've worked cooperatively with the Jefferson Buddy Program over the years. The social worker before Katie started working there had a request, and maybe they couldn't have a Buddy that matched exactly. The social worker would call us and say, "This is what I'm looking for. Do you have a volunteer on your Helpline that might meet the need?" Similarly, we've called back. So we work cooperatively to help you get the peer support that you're looking for.

**KATHRYN NOBLE, MSW, LCSW:**

Great, great. And they are really good programs, the peer support programs, because as professionals, we can help point you in the right direction, and we can be there to support you and help you. But we haven't been there. We can't tell

you what [it's like to experience] the scan. So sometimes you really need someone to tell you, "What is a port like? What is a [CT scan] like?" So that can be very important. . . .

. . . We have another program that might be of interest, too. I notice a lot of you are post-treatment. So we have a program called "Back in the Saddle" [[http://www.jeffersonhospital.org/cancer/program\\_saddle.html](http://www.jeffersonhospital.org/cancer/program_saddle.html)]. It's a one-time program. It's a dinner program. And it's for people who are finished with treatment. It's to talk about, "How do I end that, and get back into regular life?" . . . There are a lot of issues, and sometimes people are just expected to go on about their business: "Okay, show up at work." . . . How do you deal with your coworkers: [How do you deal with it when people are saying, or behaving as if], "Well, now it's done," [but] you still feel different. Or how to you integrate back into regular life? How do you deal with the fear of recurrence? How do you deal with follow-up appointments, and the anxiety that comes with follow-up appointments? We do address all of that. We also have a speaker — someone who has been out of treatment for a while, and has made that transition back into regular life. [The speaker will] . . . talk about what the experience was like [from a personal perspective]. It's kind of a good closure, and so you're all welcome to [attend] that [event]. You don't have to be a Jefferson patient for that program.

**WOMAN:**

When is that?

**KATHRYN NOBLE, MSW, LCSW:**

[The next scheduled event is on Wednesday, April 28, 2010]. . . . So I do have these fliers. I'm going to leave you my cards, too. If anybody has any questions or wants to register for any program, this is a list of all of our programs. I didn't bring one for everyone, but if you're interested in any of our programs, I have this up here.

So, that's everything from me. I really appreciate your time tonight. And I'm really happy to be here. Please give me a call if you need anything [<http://www.kimmecancercenter.org/kcc/kccnew/staff/staffdefault.php?lastname=Noble&firstname=Kathryn>]. [Applause]

**ELYSE SPATZ CAPLAN, MA:**

Well, thank you once again, Katie, for your time tonight. We're glad to connect with you. Look forward to more invitations in the future.

. . . [Please] travel home safely. Thank you.  
[END OF TRANSCRIPT]