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Neuropathy: Causes and Strategies for Getting Relief

June 18, 2008

Edith P. Mitchell, MD, FACP

ELYSE S. CAPLAN, MA:

My name is Elyse Caplan, and I am the education director at Living Beyond Breast Cancer [<http://www.lbbc.org>]. I am delighted to welcome all of you — some new folks, some returning folks. We're delighted that all of you are here. I'd like to tell you a little bit about our speaker, who's got a bio sketch that's this long. I'm sure she's got a lot of information to address on the subject of neuropathy.

Dr. Edith Peterson Mitchell is a clinical professor of medicine and medical oncology and program leader in gastrointestinal oncology at Thomas Jefferson University [<http://www.tju.edu>]. In addition, she holds the position of associate director of diversity programs for the Kimmel Cancer Center at Jefferson [<http://www.kimmelcancercenter.org>].

Dr. Mitchell is a fellow of the American College of Physicians [<http://www.acponline.org>] and a member of the American Medical Association [<http://www.ama-assn.org>], the National Medical Association [<http://www.nmanet.org>], the Aerospace Medical Association [<http://www.asma.org>], the Association of Military Surgeons [of the United States; <http://www.amsus.org>] and the Medical Society of Eastern Pennsylvania. In addition, Dr. Mitchell belongs to the Eastern Cooperative Oncology Group [<http://ecog.dfci.harvard.edu>], the Radiation Therapy Oncology Group [<http://www.rtog.org>], the National Surgical Adjuvant Breast and Bowel Project [<http://www.nsabp.pitt.edu>] and the Philadelphia Society of Medicine.

Dr. Mitchell has authored and coauthored more than 100 articles, book chapters and abstracts on cancer treatment, prevention and cancer control. As a distinguished researcher she has received 21 cancer research and principal investigator awards, and she serves on the National Cancer Institute [<http://www.nci.nih.gov>] Review Panel and the Cancer Investigations Review

Committee. Very significantly, Dr. Mitchell is the first woman physician in the [United States] Air Force to become a general; [she] is now retired from that [service]. Please welcome Dr. Mitchell. (Applause)

EDITH P. MITCHELL, MD, FACP:

Thank you so much, and thanks for waiting today. The traffic coming from downtown was ... some people say "the usual." I think it was unusual today because of the weather, but thank you. Now, of all of the things I do, what I really like to do is be with patients. I must congratulate everybody here tonight because your responses to the questions reflected what we're seeing with cancer now, and that is [that] patients are living longer. We've got better survival [rates]. There are just many, many opportunities for patients now.

I was just at the meeting of the National Breast and Bowel Project [NSABP] this weekend. The NSABP celebrated 50 years this weekend. It was one of the first cancer organizations to really address the problems of women with breast cancer. It's just amazing how far we've come. In the program that they presented this weekend they showed some of the advances we've made over the years, and it's really amazing; when you think back 50 years ago, the Halsted mastectomy, or total mastectomy — with all of the muscle, nerves, everything removed from the chest wall — that was our typical surgery. That was before tamoxifen. Cytosin was just beginning to be utilized in medicine 50 years ago, but it wasn't used for breast cancer at that time. None of the newer medications — Herceptin, Arimidex, Femara — none of those drugs had even been thought about, nor did we have lumpectomy as a major surgical procedure. I could go on and on [about] all of the things that have been discovered and [the clinical trials] that you, the patients, have participated in ... that have really afforded us the opportunity to say today that we've got improved survival. With

that improved survival, we can now reflect on a number of other issues, and I was asked to speak about neuropathy tonight.

[At first I thought,] "Why would they want me to talk about neuropathy?" Then I thought a little bit about [it and realized] it's a celebration of the fact that we've come so far, [that] we've learned so much. We have so many treatments available now, and we can say we've got improved survival... we can now think about some of those — I won't say "maladies" — but some of the long-term effects of improved survival. That is [to say], [the impact] of [side effects] that patients suffer over a long period of time, even after, long after, there's no evidence of cancer, and some of the things that we can do and are doing about [them]. I want you to join me [in this discussion]. It's going to be participat[ory] rather than my just lecturing.

Let's talk a little bit about neuropathy. How many people here have heard the term "neuropathy"? Very good, very good. There are a number of things that we can think about. Peripheral neuropathy: what is it? It's a condition that occurs after there has been some effect, some damage, to a nerve. That damage can occur in many different ways. What are some of the things we know about that are in our everyday lives that are associated with neuropathy? ... Diabetes mellitus, even when it's very well controlled, is one of the most common [causes] of neuropathies. Infections, HIV, syphilis, leprosy and a number of other infections — [those are other causes] of neuropathy. There are some nutritional deficiencies — B₁₂ deficiency; thiamine [deficiency]; these, too, can cause neuropathy. There are some inherited types of neuropathies. Alcohol, pesticides — all of these can cause neuropathies. And what about [cancer treatments]?

Drugs [used] in cancer treatment also can cause neuropathies. Radiation can. Surgery can because of the damage [it does] to the muscles. One of the major problems with the Halsted



mastectomy from years ago was not so much that there was so much tissue — the breast tissue — removed from the chest wall, but the resulting neuropathy: after you removed the muscle, the nerve and all the tissue from the chest wall, . . . many people [had], in addition to lymphedema, . . . a resultant neuropathy [that] decreased or diminished use of [an] arm. [Any] cancer treatment can cause neuropathy, whether it is surgery, radiation or chemotherapy.

A low or a malfunctional thyroid, hypothyroidism, is another. For some people, [neuropathy can be brought on by] extreme stress and hard work — and we know now it's not in your mind. It's not fictitious. Hormonal mechanisms that change your hormonal milieu can affect the nerves. I mentioned radiation therapy. It's really very interesting; [with] radiation therapy the effect can come many, many years after the radiation has been completed. [In] some patients, five, six, seven, even 10 years after treatment for cancer, neuropathies can occur.

Then there are some tumors that are associated with neuropathy. For example, [with] some breast cancers, the cancer itself can cause a neuropathy, especially if there is metastatic cancer — lung cancer . . . is highly associated with development of a neuropathy. For some patients, the neuropathy might be the first indication that something is wrong. [In] the development of metastatic disease [in] some women who have been without metastases and who have been free of any evidence of breast cancer, breast cancer recurrence may be indicated by the development of a neuropathy. So we have to look at those also.

Symptoms of neuropathy. What are they? They can be almost anything, and it depends on which of the nerves are affected. What do I mean by that? The neuropathy can affect just the nerves to the skin. If the nerves to the skin are affected, we are looking at symptoms that might be numbness and tingling or a feeling that you're wearing an invisible glove. There can be extreme sensitivity to touch, a burning feeling in the toes or fingers [or] sometimes a cold feeling. Or there may be the inability to even feel cold or heat. There may be difficulty with writing or difficulty feeling any kind of object. Some people have difficulty feeling where their feet are located.

Internal organs may be affected. There can be effects of the bladder. There can be effects of the intestine — some people call it a slowed intestine, or decreased motility. There can also be sexual

dysfunction. If the nerves to the muscles are affected, there can be muscle weakness. There can be muscle cramping, spasms. Many people have a sense of clumsiness in that they can't determine where their feet are, so there may be difficulty walking, difficulty going up steps and difficulty with balance. It just depends on which nerves are affected — whether they are the muscle nerves, the internal organ nerves or nerves to the skin. . . . Sometimes just fatigue, [the feeling of being] tired, can be the problem. All of these — clumsiness, difficulty with balance, dizziness, cramps — can be symptoms. Most often [it is described as a] burning or sharp, shooting pain. There can be loss of reflexes, loss of muscle. There can be muscle wasting. The muscles in the legs or the hand sometimes become very, very small and not usable.

What starts all this? This represents a nerve. For chemotherapy-induced neuropathy, you have what are called neurons. [They] allow the nerve communications to go from the brain to the nerve. [They] go all the way to the lower extremities; all the way over. When chemotherapy affects these nerves, it affects this communication channel all the way down the nerve. Therefore, what the brain tells the hand to do no longer works; the hand is ineffective.

How does [neuropathy] present? It can present at any time. Some patients may develop the neuropathy while they're on treatment. Other patients may develop the problems long after treatment has been completed. The neuropathy can sometimes get worse; it can get better. There can be tremendous variation in what patients experience. There can even be damage to some of the internal organs so that blood pressure might not be maintained. For those people, when they move from the sitting to the standing position, they may pass out, have difficulty standing [or have] difficulty in getting up from the sitting or laying position. Some people will come in the office and tell me, "You know, when I get up in the morning, I have to sit on the side of the bed for a while before I get up and move." Again, that's a symptom of peripheral neuropathy. Everything along that nerve is either not moving correctly or moving too slowly so that the body doesn't adjust. Those are the things that happen.

How do we diagnose [neuropathy]? It's really hard to diagnose. You really have to depend on what the patient tells the doctor. There are very few tests that you can do to measure neuropathy. What one patient tells you may be totally different

from what another patient tells you. What you have to do as a physician is judge how severe [the neuropathy] is by [evaluating] exactly what the patient tells you. I'm going to say [this] over and over tonight. Make sure you tell your doctor exactly what happens when [you experience neuropathy] — how it happens; how frequently [you experience symptoms]; how long it lasts. Has it gotten better? Has it gotten worse? What kinds of functional things are impaired? Are you having difficulty with buttons? Are you having difficulty walking? Are you having difficulty getting up from the lying or sitting position?

There is no test. Usually [when something is wrong,] you tell the doctor, "It hurts here," or, "I have a cough here," [and] you get a chest X-ray. You've got a lump here; you get a mammogram. You get a CAT scan or whatever. There is no real good test that anybody can do that measures neuropathy. . . . [But here are some of the ways a doctor might go about assessing the condition.]

[An] . . . assessment of symptoms and [a] clinical examination [can be done]. This is the first test to do. . . . You've got to be very careful with it: it requires [very clear, specific] communication, because there is intra- and inter-observer variation. What one doctor tells you might be totally different from what another tells you, and that's because [each doctor must] sit and listen to what the patient [describes and evaluate the patient's condition based on what he or she has heard the patient say]. It takes a long time, [and] everybody has a different mode of how they listen to you.

We can do a vibration threshold, . . . but it's not very sensitive. Sometimes we can do . . . nerve conduction studies [or] needle electromyography. Those tests are okay, but they don't tell you how severely impaired one person might be. You might have a markedly abnormal conduction study for one patient [who doesn't] seem to have any problem; [the patient is] moving and doing all of the things [he or she wants] to do. Another patient's test [results] might not be so bad, yet what they do functionally — they'll tell you, "I can't tell where my feet are. I stumble. I can't go up stairs very easily. I can't write anymore," or, "I can't feel with my fingers. I have to get somebody to tie my shoes. I can't button my buttons." So really, what we're looking at is the functional impairment, because sometimes it can be very severe.

Now, the best test, or the most accurate test, is a nerve biopsy. A nerve biopsy can be done, and . . . it's confirmative. It will tell you what the damage



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to the nerve is. But it is invasive, and any biopsy on the nerve — guess what it's going to do?

SEVERAL PEOPLE:

Make it worse.

EDITH P. MITCHELL, MD, FACP:

Make it worse. [The biopsy is] going to [cause] more permanent nerve damage.

So, there really is no good test to measure neuropathy. It depends on communications between the doctor and the patient. . . . We will grade the patient according to functional disability. . . . this is a National Cancer Institute grading, and it's simple. It's one, two, three, or four. It's based on how disabling [the neuropathy] is to the patient. So it's very important for you to tell us, because somewhere we're going to write in our record the grade. If [the symptoms do not cause impairment,] the patient might tell you, "Well, yeah, I can feel the tingling in my fingers or toes, but it really doesn't affect me. I can do anything I want to do." We'll label that as a grade one. Then it gets worse as it goes up to four; four [indicates] a totally disabling or life-threatening situation. You say, "How can neuropathy be life threatening?" Well, if a person is falling, that could be life threatening. If the patient gets up too quickly and passes out, injures [his or her] head, breaks a bone — those [events] can be life threatening.

[Assigning a grade is a way of indicating the] kind of disability the patient is experiencing. This is what insurance [companies] look at. . . . Grading is very important; that's why I say that communication between the patient and doctor — telling me exactly how impaired [you are], how long [the neuropathy has] been there, what makes it worse, [whether it's] getting worse or better, and other things [— is important]. This [communication gives us more information to use when] . . . we examine the patient; [it helps us to determine the] kinds of things we're going to look for [during the] examination of the patient.

We'll then examine the patient. Once we do that, we're going to be looking for other things that can affect neuropathy. For example, diabetes. As the population ages, the incidence of diabetes goes up. Let's say you have someone who developed a neuropathy from breast cancer treatment and then later develops diabetes; there could be neuropathy from the diabetes in addition to neuropathy from cancer treatment. Add them all together, and it's going to be worse. [Here are some other] things we're going to be looking for: Are

there other problems? Does the patient have B₁₂ deficiency? We're going to be checking B₁₂ and [making] other nutritional assessments. Does the patient consume a lot of alcohol? Alcohol will make it worse. We're going to be looking for all of those other [factors], all of those other things that might have an effect.

Sometimes patients don't even associate [their neuropathy] with their cancer treatment because, as I said, it could occur many years later, [and you may not] even think about . . . the radiation [you had] 10 years ago or the chemotherapy [you had] 10 years ago being associated with problems that develop now. That's all a part of patients having improved survival; [such situations are the result of our having] better treatment, better survival. Now we're talking about survivorship. [With people who have survived] breast cancer or other cancers, [it's] very, very important to make sure we take into account all of these things that can occur later down the road, and make sure that we are incorporating them into the patient's evaluation.

Approaches to management. There are lots of ways of managing peripheral neuropathy. Again, a lot depends on the impairment. What is the patient experiencing? I usually use what we call a multimodality approach. First of all, there is no specific medicine available that can [be given to every patient or that will] give improvement to every patient. Medications may be difficult. What kinds of patients do we expect to see problems in down the road? All of these types of cancers can occur, and all of these have been highly associated with neuropathy in survivors. Lung cancer [is] probably the number one cancer that causes neuropathy, but breast cancer, ovarian [cancer], prostate [cancer, and] many others [do as well]. All of these cancers can be associated with significant neuropathy.

What else can make it worse? There are lots of things that can make neuropathy worse or that can affect its progression as the patient goes forward. One of them is one of the — I call it side effects of survivorship. But that's a great one. The alternatives to advancing age? Not ones that we want to talk about. I don't even call it "advancing age" anymore. I just say "chronologically blessed." (Laughter) But those patients — as one ages, you'll find more of the neuropathies. [As] younger patients who receive therapy . . . age, you're going to see more neuropathy. [When a] patient who is over 65 undergoes cancer treatment, [he or she] may have

more neuropathies than the patient who's 35 at the time [he or she] undergoes therapy. [With] advancing age — [with] being chronologically blessed — you'll see more neuropathy.

If there's a family history of problems that cause neuropathy, [such as] a family history of diabetes — if the mother, grandmother, aunt and others have had diabetes, [of if they] have had B₁₂ deficiency — those [present] increased risk for an individual. . . . Knowing family history [is important,] not only [in terms of] breast cancer and [other] cancer, but [also in terms of] other problems that the patient can have. Malnourishment: If individuals are on unusual diets; diets where there is not consumption of a lot of different foods — and you say, "How do you get that in 2008?" There are lots of [such] diets. People who are on vegetarian diets will exclude animal products. One of the best sources of B₁₂ is eggs . . . if someone is on a 100-percent vegetarian diet and is not consuming any animal products, B₁₂ deficiency can be significant. As people become chronologically blessed, B₁₂ deficiency also is a measure of age. We see it more commonly in individuals over age 65. Excessive use of alcohol [is] another [factor in neuropathy]. There are also some medications that . . . can affect it: antihypertensives; diuretics. One of the greatest influences on neuropathy is a low potassium [level], and, of course, many of the diuretics — all of the thiazides; Lasix; those type of diuretics — can affect potassium [levels]. Being on other medications that can affect the nerves; that's a problem. So we'll want to get all of that information. It's very important to know which medications you're taking [and to] make sure that you discuss them with the doctor. There are also some complementary medications and other preparations that we sometimes don't call vitamins or . . . medications that . . . can accentuate neuropathy. One of them — how many people have heard of Saint-John's-wort?

WOMAN:

I have.

EDITH P. MITCHELL, MD, FACP:

That's one that can affect the nerve tissue. So it's very important not only to tell the doctor what you're taking, but — I always ask my patients, "Now, are there any other things that you take? I want to know [about] your vitamins. I want to know [about] aspirin. Put down everything that you take so that we'll know that." Then I always



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ask if there are any special dietary situations that the individual might have, especially if [he or she is] not consuming any kind of animal products.

Now, chemotherapies: Some of the[se] chemotherapy agents are used to treat breast cancer and some that are not. Misonidazole, for example, is . . . used to treat fungal infections. Another is in the medication Flagyl, which is used to treat different kinds of infections. So there are antibiotics — there are lots of different medications — that can make the neuropathy worse.

Can a survivor experience neuropathy during, immediately after and/or years after treatment? All of the above may occur. Some people will develop neuropathies while they're on treatment. Others might develop them a little bit later, and then some individuals, many, many years after treatment. There are some [neuropathies] that are often ignored by both the patients and healthcare professionals because you don't associate them with a treatment that you had many years ago. Even though you may have been cured of cancer — it may have occurred 15 years ago — it's [still] very important to have that survivorship examination. It's now even a buzzword, "survivorship," because there are more and more individuals who have survived cancer. As I mentioned here, for some patients, the neuropathy may be the first sign that the cancer is recurring, or coming back.

Can neuropathy be cured? The nerve tissue does have the propensity to heal. It does so very slowly, however, and [healing] may occur over a long period of time. In most situations [neuropathy is] difficult to treat, especially in patients [who have] gone through cancer treatment. [Neuropathy] might occur later; it might take many years to improve. Unfortunately, some patients never recover from the neuropathy. In other words, we never cure it. There are a number of treatments, however, that can help the patient.

First of all, we look at nutrition. We make sure that the patient has adequate vitamin [levels]; that there are no vitamin deficiencies, especially [of] thiamine and B₁₂. We look for any conditions that might be contributing to [a] worsening [of the neuropathy]. We make sure that thyroid function is okay, make sure that there's no evidence of diabetes [and] look for any medications that might be affecting the patient, and then we begin to work with pain medicines [and] physical therapy. All of these [treatments are] important. For clinical trials, [which are] very important [in finding new

therapies], and we're doing a lot of clinical trials now [that are] looking for other medications that might give improvement.

Exercise is one of the best things that you can do for peripheral neuropathy. It can increase strength, circulation and coordination. With a physical therapist, [you can work on] impairment in balance, impairment in any organ or impairment in any structure — hand function; leg function — the physical therapist can help us with this. We will frequently tell patients, "Go to a physical therapist." One of the things that I find very helpful is water exercises or swimming in a warm pool. The support that water gives you [as you] exercise is very important. . . . If there is not a warm pool available, [a soak] in a warm bath, with some exercises following that warm bath, can help many individuals.

Massage can be very important to increase circulation and promote relaxation. Whatever kinds of things you can do to relax and then exercise that muscle and the affected areas are very important. But [these activities] must be done under the guidance of a physical therapist, a physician or some provider who knows what [he or she is] doing to make sure that you're not doing additional damage to the area.

Another thing that we have to [focus on] is safety. If there is difficulty walking, you want to make sure you remove sectional rugs or other items that [you] could trip over. [causing you to] fall and [incur] further injury. You want to make sure that the atmosphere, the environment, the home, is very safe. You want to make sure that lights are close by so [you don't] have to fumble in the dark. Use a lighted key ring if [you] need that to help [you] unlock doors. Remove throw rugs that could cause [a] fall, and make sure there's no clutter in paths where [you have] to walk. We want to make [the environment] safe.

You want to make sure that [you wear] sturdy shoes, very comfortable shoes, and [that you] avoid slippers and other [footwear that does not allow you to] feel where [your] feet are. You want to make sure that [you] are wearing protective shoes. If there are spills, make sure that they are removed very carefully. [In] the shower and bathroom, make sure that there are appropriate [assistive tools] to help [you] if [you] need that. Make sure that everything is safe.

Another [factor to consider is this]: How will a cancer survivor's life change if he or she has neuropathy? Well, life changes, and those things

that we have to adapt to, [that] we have to put up with — call them whatever you want — again, it depends on the circumstances. What areas of the body are impaired? How severe is that impairment, and how much does it interfere with a person's function or lifestyle? Pain and other symptoms may be mild or severe. Each person's impairment will be very different. Each survivor's experience will be very different. However, with appropriate treatment, the effects of neuropathy can be limited, and the progression of neuropathy can be stopped so that individuals are not so much impaired. Rehabilitation and other treatments can [help, and they] are very important. Your physician can help you with this.

[Neuropathy] might make standing or walking very difficult. Writing can be difficult. Balance can be affected, [increasing] the risk of falling. Participating in activities — [even] just simple things, like buttons and tying laces — [can be difficult]. There can be insensitivity to heat or cold because, for many people, that burning sensation causes loss of heat and cold feelings. I have one patient who comes in the office all the time with burns, and I ask her, "How did you get this burn?" "I didn't even feel it, Doctor. I was cooking and I looked down; my hand was burned." So you want to be very careful there. . . . "Well, I dropped a cup of coffee on my hand, and I didn't even feel it. I was just going on about my business and looked down." We want to make sure that these individuals wear the appropriate clothing, aren't exposed to [damaging] cold or heat and are protected. For the caregiver, for the family member, helping that individual can be very, very important, and that's an important part of the management [of neuropathy].

There can be a lack of pain sensation, so we have to pay very careful attention to the hands and feet. There may be cuts. There may be injuries that the individual doesn't know about. [We may] ask, "How did you get that cut?" "I don't know. I don't remember." [He or she] didn't feel it. Driving can be [a] very, very important [concern]. If the individual cannot feel where [his or her] feet are, . . . [that person must] either stop driving or have a car adapted with hand controls. [Neuropathy] can slow your reaction time [while] driving, and that is a cause of many individuals having injuries, having accidents in later life, because, as I said, the movement down that nerve is slowed. There is slow movement of the feet from the accelerator to the brake It's really important for others to offer



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individuals [with this problem] assistance. Offer to drive them; encourage them not to drive.

Loss of independence. One of the greatest problems with individuals as they age is that loss of independence [or control]. Dad used to be in control, and now he's not in control anymore. We've got to be very careful with that, because that can trigger depression; one of the consequences of peripheral neuropathy is depression. Good communication to your healthcare team is very important.

[There are some] medications that we use. Neurontin and Lyrica are the two drugs that are probably most frequently utilized now, but there are lots of different medications, even some that are over-the-counter. Capsaicin is a red pepper ointment that, in many situations, I prescribe for people, because that tends to help more than anything else...

If there are cramps associated [with neuropathy], believe it or not, tonic water is one of the best things that you can [take]. [In those situations] I'll tell [patients] to try drinking some tonic water. We used to prescribe quinine a lot for this, but it's hard to find quinine now, so tonic water [is recommended, and it's] very good.

Just talking with the patient and making sure that, as a provider, I am asking questions down the road after the patient has been treated [is important to me]: "Are you having any problems? Tell me about it." Sometimes patients won't [bring up a problem] because they think it's not related to the cancer that they had many, many years ago. So I always ask these questions. And the patients should always ask [questions such as], "Doctor, could this be related to that Cytoxan or other drug that I took for breast cancer many years ago?" So make sure you ask that.

Complementary medicine. Many times I'm asked about complementary medicine. The ones I showed you just before, those have all been proven, and capsaicin is controlled by the FDA, so it is medicine. But there are some other [forms of complementary medicine] that are not controlled by the FDA but that could be important. TENS, or magnetic field therapy, is the stimulation [of nerves via] a battery-operated device. Acupuncture can be very important, and biofeedback [is] another important mechanism of treatment. Some patients have to put together a plan that combines [several] of these kinds of therapies. [Such a plan] might include some drugs, some biofeedback [and] relaxation therapy. [It

might include some water [therapy], sports or physical therapy. All of those things might be necessary for some individuals.

Transcutaneous electrical [nerve] stimulation, or TENS — a lot of patients do find that important. Relaxation, massage, monochromatic infrared therapy — these are all things that physical therapists will have available and could utilize for patients. [We also need to address] psychosocial considerations. Again, [it's about] the physical and material well-being [of the patient]. In some people, if there's chronic pain, inability to function, depression can occur. Psychosocial functioning is [a] very important [concern]. You've got to worry about relationships; social activities; career; pursuit of intellectual interests. All of these can be affected by a peripheral neuropathy. Ability to work; ability to garden. . .

I actually have a patient now. I just thought about him. I saw him this week. He loves to boat, and he has a huge boat. His big problem now is [that] he has difficulty climbing over into the boat because of peripheral neuropathy. It can really affect us in a number of ways, and we've got to be very careful about that. [The issue is] quality of life. You can imagine [that,] if all of these things are going on, quality of life can be impaired, as well as the quality of life of the family, because when one family member is impaired, this affects other individuals. Sleep disturbances, feelings of isolation, sense of disappointment, depression — all of these things can occur. And many times we think about these and we say, "Well, Grandma is getting old." Well, it's not just that Grandma is getting old. It could be a peripheral neuropathy, and many times the patient just hasn't communicated that.

So, things to ask the doctor: these are things that I thought of; I'm sure you can tell me some more, so I'm going to be asking you what I can add to this [list]. You'll want to [make sure you tell] the doctor . . . when the [pain or impairment] occurred — when it started — how long it lasts, how severe it is, whether or not it impairs function and what [the neuropathy] does; exactly what happens. You want to know what techniques are available that might help, that might give some improvement.

What resources are available for education and support? There are some websites. I like the one from the National Library of Medicine [<http://www.nlm.nih.gov>] . . . If you go to the Internet, you can find almost anything and everything, but there is a good site from the National Library of Medicine that really gives very good information on peripheral neuropathy and resources.

How can my condition affect my relationship with other members of the family? You want to let people know. For example, if Grandma has to get up at night to go to the bathroom and [she] knocks over something, everybody wakes up. So we need to make sure that there is a well-lit bathroom, and so forth. I guess I'm telling you that because in my family we took care of several of my relatives. My great-grandparents lived in my home, and then my grandmother. And at one time we had my father's mother and my mother's mother both, at the same time, in our house, so I have a lot of personal experience in helping family members.

What steps can I take to improve my quality of life and gain more control? You want to ask . . . your doctor what you can do. For example, if there's difficulty with driving, you want to ask the doctor, "What can I do?" Not all of us have the resources to get an automobile that is equipped [with hand controls], and the doctor can give information [on financial assistance that may be available for assistive devices]. Many of the tools that we need for patients are covered by insurance, so if you ask us, we can help you with [securing] equipment. For example, for bathroom adjustments, there are individuals who will come to your home, assess the situation and then give me a recommendation on what equipment is needed. Medicare and many other insurance [agencies] cover [such equipment].

Are there any neuropathy or chronic pain support groups? Talking to somebody else who's been through this or who is experiencing some of the same problems with neuropathy can be very important, so groups like this — where there are other individuals, other patients, who might have experienced this — [are] very important.

Are there any clinical trials? As I mentioned, now that we have more [cancer] survivors, we are beginning to look at some of these other kinds of treatments that will help patients be more functional. I say these are the clinical trials for survivors. Here is a clinical trial service that looks at peripheral neuropathy [<http://search.centerwatch.com/default.aspx?&sf=fI&ia=Neuropathy&rg=&dn=&pc=&cn=&ct=&ln=>].

So in summary, my hat is off to everyone here for your participation [and] for your surviving breast cancer, and to the caregivers and other family members who have supported you through that. We've got better survival, and one of the consequences of survival is peripheral neuropathy.



It's one of the most common side effects of treatment; it's very common. Don't think that you are in this by yourself [or] that you're the only person [who's experienced this]. [Neuropathy is] one of the most common side effects. It's also one ... that is [most commonly] overlooked, undertreated and, therefore, ignored.

We want to use clinical assessments and tools to monitor the patients. I teach my patients how to monitor themselves. For example, after I start a patient on a new treatment, I will say, "Now, you notice how you button your buttons. This is what you're doing today." I will ask patients to walk on their tiptoes. "This is what you're doing today. Let me know in two weeks, or some time later, how this is doing." Being able to assess levels of [and any changes in] impairment ... is very important.

These are the chemotherapy agents. The incidence is similar, but they can be managed. Chemotherapy-induced peripheral neuropathy can be managed. Radiation-induced neuropathy can be managed. If the patients develop [neuropathy] while they're on treatment, we can sometimes do something about that by either increasing the length of administration time ... sometimes I'll just, instead of giving the chemotherapy over [the course of] a half hour, give it over [the course of] an hour, and that can affect patients. Then, sometimes, giving calcium and magnesium can be very important.

As I said, I had the experience of [having] both my great-grandparents in our home, and then my father's mother and my mother's mother [in our home] at the same time. My great-grandmother would bathe her feet in Epsom salts every night. She swore by them. She would soak her feet, and then we would dry them and rub them with different things. Does anybody know what Epsom salts are?

WOMAN:

Magnesium.

EDITH P. MITCHELL, MD, FACP:

So you come in my office now and I will give you a magnesium-infusion IV. And guess what Epsom salts are? Magnesium. Some of these things that may have been utilized for a long period of time — we think they're not medicinal, [but] they really are. Some of these [are] medications that we've forgotten about or that we've kind of poo-hooped. What does [magnesium] do? The nerve tissue needs magnesium to function; if your body's magnesium [level] is low, the nerve tissue won't

function as well. One of the methods that we [use to] treat patients in the office is magnesium [given via an] IV. You can sometimes give it by mouth, but that causes diarrhea — one of the things that you give when you need to kind of move things is milk of magnesia or mag[nesium] citrate. So giving it orally doesn't always work. But because the nerves — if the skin nerves are affected, or the feet, especially — just soaking them in Epsom salts allows absorption of some of that magnesium. So those kinds of things are very important.

WOMAN:

[Inaudible]

EDITH P. MITCHELL, MD, FACP:

I never thought about it until I figured out, actually just a few years ago, what Epsom salts are. Yes, go ahead. Questions now. Let's everybody participate.

ELYSE S. CAPLAN, MA:

How about if I just thank you, and then we'll move to the questions. Okay? (Applause) I was saying to Amy, my colleague back there, "What an amazing presentation." You covered a very, very focused topic in such a thorough way. Everybody was paying attention. We really appreciate [that you not only covered] the medical/clinical aspects of it, but [that] you [also] talked about the psychosocial implications, the quality of life — which, of course, ties into LBBC's mission, to empower everyone to live with the best quality of life. You really integrated the day-to-day stuff with the complicated medical stuff, and we appreciate it. (Applause)

Before we move to the questions, I want to say [that, in the past,] Epsom salts [were considered a] cure-all. It's such a generational thing. My personal anecdote, to [add to] yours: my father owned a pharmacy for many years, and I worked, as a young teen and all through college, in my dad's drugstore. We sold cases and cases of Epsom salts. They were cheap, and they were [considered] a cure-all. I will always remember [that]. So now we have a better understanding [of that product's function].

WOMAN:

[Inaudible] for about 20 years, and [inaudible].

EDITH P. MITCHELL, MD, FACP:

I don't think so, but I don't recommend using old medicines, period. Go get a new box of Epsom salts.

ELYSE S. CAPLAN, MA:

I know you all have a lot of questions, but I would like to kick off [this portion of the presentation] and ask two quick questions. I'll [ask] both, and [then] you can take it [from there].

Does an early diagnosis of neuropathy, grade I, lend itself to more effective treatment? Does it make a difference — because it is overlooked, because it's not often reported or recognized — if someone is caught at that more asymptomatic [stage] or [if] you're not really feeling that it's complicating your life — is the intervention more successful?

EDITH P. MITCHELL, MD, FACP:

Absolutely. The earlier you find neuropathy, the better we are able to manage it. It's so important, because you want to find other things that could be important, like diabetes. If there is even just a little abnormality of the blood sugar, that can cause neuropathy, and for the patient who might have that grade I, that can make a grade I go to a grade 2 and make the impairment worse. So the longer the delay in diagnosis and treatment, the more severe the impairment will be and the higher the grade [will be]. A grade 2 could go to a 3, a 3 to a 4, and so forth.

ELYSE S. CAPLAN, MA:

Thanks for answering that. That, again, reinforces what you said throughout about communication with your doctor. So, even the littlest things that may seem like nothing — you need to report [them], because your doctor is going to be tuned in to some of the more subtle symptoms that you might feel. My second question is [this]: You mentioned that neuropathy could be, in some cases, the first sign of a recurrence. Can you explain why that is?

EDITH P. MITCHELL, MD, FACP:

Nobody really knows, [but] it's probably because the cancers make substances. They also cause an inflammatory reaction: the white blood cells produce substances called cytokines, and those cytokines are the same cytokines that cause inflammation. So if you've got arthritis and there is soreness, swelling, [in or around] a joint, that's in some ways produced by cytokines. For cancers, the production of cytokines, inflammatory areas. For some patients, pain in an area might be the first sign [of a recurrence], and that [pain is] caused by cytokines and the substances that either the cancer produces or the white blood cells produce in response to the cancer.



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ELYSE S. CAPLAN, MA:

Thank you for clarifying that.

WOMAN:

My first question — because you were talking very early [in the presentation] about nerve damage — I have trigger finger. Could that be a form of neuropathy?

EDITH P. MITCHELL, MD, FACP:

Yes, absolutely. For the patient who has had breast cancer, especially if there's been lymph node dissection and then radiation, there is a lot of damage to the nerves, both from the surgery and [from] the radiation and probably the chemotherapy also, and that can sometimes lead to swelling in the hand, or lymphedema, and that can result in tendons being stretched, and what you have with a trigger finger is an inability to move some of the fingers as they normally have. That should be discussed with your doctor. And ask [your doctor] for specific recommendations. This is something that can occur years and years after breast cancer treatment. It doesn't have to occur right after [treatment].

WOMAN:

After having breast cancer ... I'm an 11-year survivor, then I got diabetes. But I was sort of predestined to it because of my large babies and the history of diabetes in my family. Here I'm popping up with diabetes. Now my siblings have diabetes. I was talking to the doctor about it. He said it occurs with people who are excessive drinkers. I wasn't that. He knew I had breast cancer. Then he said, "Well, that's also because of your diabetes." So now I'm hearing about nerve damage and cancer, so I'm saying, what does that mean? I went to a doctor, and he wanted to do the operation, but then he said there was no guarantee that it would disappear.

EDITH P. MITCHELL, MD, FACP:

That is correct. That's why I say you might have to have a treatment plan that involves all of those therapies — relaxation, exercise, medications — all of these, because there's no one [treatment] that's going to take care of every patient. This is not an instance where one [size] fits all. You might have to try some of these different [treatments]. Even the medications can cause problems. For example, if there is hypertension or heart disease, or just in some patients taking Neurontin — I can give one patient a Neurontin prescription, and they'll tell me, "Oh, Doc, I can't take that medicine.

It makes me too dizzy," or, "It does this," or, "It makes me too sleepy." That's why I say [that] communication is very important. When did you first feel the trigger finger? How long has it been there? How rapidly is the impairment progressing?

WOMAN:

[Inaudible] because sometimes [inaudible] and it just hurts like crazy to bring that finger up, and I scream when I bring it up. [Inaudible] but it's about five or six years after ...

EDITH P. MITCHELL, MD, FACP:

The breast cancer treatment.

WOMAN:

[Inaudible] But it seemed like my diabetes occurred, like, two years after.

EDITH P. MITCHELL, MD, FACP:

Sure. This is one of the things we're doing with survivorship programs. If you ever have any chance to talk to your congressmen [or congresswomen] about financial support of survivorship programs, get the message to them. Because not all doctors, nurses and other healthcare providers know about these long-term effects of cancer treatment.

ELYSE S. CAPLAN, MA:

That's a good point.

EDITH P. MITCHELL, MD, FACP:

So your doctor might not know.

WOMAN:

I wanted to find out — I've had some peripheral neuropathy in my fingers and my toes. It's especially bad in the toes. I'm two and a half years out since the end of treatment. It started out just at the tip of the toe, and now, two and a half years later, it's working itself into the ball of the foot. I notice that sometimes the toes feel like they're sort of ... not exactly cramping up, but they're pulling themselves together. I think it's going to affect my walking soon, and part of my job is walking from one place to another, a lot. I can't stop working, because I love it. Part of my staying healthy is going to work occasionally. I find [that] lately I've been tripping a little. The other thing you mentioned — I was diagnosed with high blood pressure not too long after getting the chemo treatment. That was a big surprise to me. Even though I have a big family history of hypertension, I'm a stress reduction specialist, so I'm not supposed to ... (Laughs) So I really think that it's because of the chemo.

EDITH P. MITCHELL, MD, FACP:

It could have been. Did you get Taxol or Taxotere?

WOMAN:

Yes. Taxol.

ELYSE S. CAPLAN, MA:

Have you spoken to your doctor about it?

WOMAN:

Oh, all the time. Every time I go there ...

EDITH P. MITCHELL, MD, FACP:

That's very typical of the taxanes, Taxol or Taxotere. Ask your doctor to refer you to someone who has experience with this; [that person] can help you. You also want to make sure that you don't have B12 deficiency or some other — hypertension, as you say — some other condition that I don't say is related to being elderly anymore; it's [related to] being chronologically blessed. [It's important to make] sure that there are none of those things. But this is a very typical Taxol effect.

WOMAN:

That's what I heard. I thought maybe it is possible that — because my back has little things, chronologically blessed problems — maybe there is a problem there, and [that] I should go to a chiropractor. Maybe if there is some nerve instability there, some way or other it's affecting my toes.

EDITH P. MITCHELL, MD, FACP:

Well, what I try to do is use a combination of things to help patients, but first of all I'd like to make sure that there is no damage to any area, so I wouldn't ... my own personal feeling is, don't go to a chiropractor right away until you make sure that there are no areas that need medical attention that's separate from what a chiropractor would do. Then, after you make sure that there are none, you can add on physical therapy, swimming or water sports, chiropractor [treatments], acupuncture — all of those things. But I would like to make sure that it's all a part of one plan [and that] you've got one person, one healthcare provider, who's in charge of the whole plan [and] who can help you with various parts of it because, I can tell you, once there's peripheral neuropathy, in most cases it's going to get worse before it gets better.

WOMAN:

It can get better?

EDITH P. MITCHELL, MD, FACP:

Yes. It might get better. That is correct.

WOMAN:



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It might. It's not necessarily so, but it might.

EDITH P. MITCHELL, MD, FACP:

It might. That is correct. Every patient is different. But there are some things we do to improve patients, so some patients will definitely get improvement.

WOMAN:

You mentioned earlier that there might be neuropathy associated with hormonal changes. For those of us that had hormone positive cancers and are now ... for example, in my case, I'm on Arimidex, [and other people] might be on one of those other [medications] — could that be associated with some kind of an increase in the neuropathy above and beyond what most of us, I suspect, got on the taxanes?

EDITH P. MITCHELL, MD, FACP:

The answer is yes. About 30 percent of patients on Femara, Arimidex or Aromasin will have unexplained muscle aches, pains, cramps — something. Every patient describes it differently. But it is the number one [reason] patients stop taking, discontinue, those medications. So it's really very important. Peripheral neuropathy, pain or discomfort, musculoskeletal aches — whatever you call it, that's one [side effect] that is fixable. The discomfort from Arimidex — many times medications like Naprosyn, Advil and so forth do wonders for that. Talk it over with your doctor and make sure that there are no contraindications for those medications.

WOMAN:

My concern was really more for the symptoms, the specific numbness and tingling, which seem to be worse. I just wondered if there was any relationship between the antiestrogen drugs and the specific neuropathy symptoms like numbness, tingling, et cetera.

EDITH P. MITCHELL, MD, FACP:

There is definitely a relationship. The neuropathy that occurs from the taxanes — Taxol, Taxotere — [that are administered] before you start the antiestrogen therapy can certainly be worsened by [the antiestrogen medications]. Talk to your doctor about it. These are some things that can ... be done to give you some comfort.

WOMAN:

We have several questions up here — we're from a group. We'll start with [what may be] the hardest one. ... I'm fighting neuropathy from different things: the surgery; the radiation; the

medication; a car accident; [and] surgery when I was a teenager or an adolescent. [I have] a lot of numbness. I had [a] mastectomy. I have no feeling on the front of me at all, and I'm starting to trip over rugs and all those kinds of thing. My family doctor doesn't think any of this ... she just wants me to walk more. And I had Fareston, which nobody seems to know anything about. I stopped taking it after five years. I don't know if I should be on it. I don't know. There are so many questions with the medication.

EDITH P. MITCHELL, MD, FACP:

You've got the cancer, the cancer treatment and its consequences, plus you have the basic things that occur with life: diabetes, hypertension, auto accident, teenage injuries. All of these things can contribute, and you've got to have your doctor sit down and try to put the pieces together. . .

WOMAN:

You need to change doctors.

EDITH P. MITCHELL, MD, FACP:

There are some individuals who are good at that, and I would be happy to help in any way I can.

WOMAN:

Yeah, I need a lot of help. That's part of the problem. They don't understand. The insurance industry is another problem. They make things worse, if anything. But, again, Fareston: Has anybody taken Fareston besides me? Am I the only one?

WOMAN:

One other person.

EDITH P. MITCHELL, MD, FACP:

There are some other people who have taken it.

WOMAN:

One? Gee.

WOMAN:

Do you have an oncologist following you?

WOMAN:

Well, no.

EDITH P. MITCHELL, MD, FACP:

See, what we do ... years ago it was typical, once the patients got to five years or so [of being on the medication that] the oncologist didn't follow them. I'm seeing patients now continuously, and I have a plan for those patients at five years, 10 years, 20 years. I can work with their primary care doctors

to help with that. We do a lot of educating [of] physicians because, as I said, many physicians don't know about these kinds of things. There are very few patient education areas where you can get information, and it's groups like this that, I think, are going to make a difference [in that], number one, we begin to talk about these things. But so frequently we keep them to ourselves. What some of the psychiatrists say is that patients don't tell you because they're afraid of what it might mean. So it's really very important to communicate about it and see ... there are some things that can possibly be done. But you've got to go through the total evaluation, and there is no one answer for every single patient.

WOMAN:

How do I start?

EDITH P. MITCHELL, MD, FACP:

I think to start with your primary care physician or whatever person you go to.

WOMAN:

[Inaudible] She doesn't know [inaudible].

EDITH P. MITCHELL, MD, FACP:

Then ask her for a referral or [get] a consultation from a rehab specialist. That's one area where you might get some help. I use rehab specialists a lot. Just [getting] a second opinion from another physician, an internist, is another good way to start — [a] second opinion from an internist or another cancer specialist.

WOMAN:

I'm in the same situation. I had polio and, of course, a lot of other problems, too. I was wondering: with neuropathy, would hand tremors or jerking, like this, of the foot — would that be a symptom that might go along with neuropathy? I understand it's not an absolute answer. It could be [due to] other causes, too.

EDITH P. MITCHELL, MD, FACP:

Sure, it could be.

WOMAN:

But could it [be associated with neuropathy]?

EDITH P. MITCHELL, MD, FACP:

Yes, it could be. That is correct.

WOMAN:

I wondered, when you spoke of malnutrition and B12 and thiamine deficiencies: Do you monitor them just as a baseline and, if they're normal, proceed [with treatment or other evaluations]? Or does a patient have ongoing checks of [those



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levels]? Also, when you were talking about a plan of care and who drives the plan of care — one thing we've learned is to get copies of everything so that we have a personal health file [on hand in the event that we] go to another specialist.

EDITH P. MITCHELL, MD, FACP:

I think the patient is in the best control when [he or she has] that information, or you can ask the questions [of your doctor] where you have the answers about family history, previous treatment, X-rays, at any time. I do encourage people to keep as much information as possible. When patients come into my office, I usually have an extra copy of their X-ray reports right there so I can say, "Do you want a copy?" Or, if they ask for one, I can say, "Here it is, right here," so that you've got all of that information. Do I recheck things? Yes. Take B₁₂ levels[, for example:]. Normal is 180 or higher. If I have a patient with minimal symptoms and a B₁₂ [level of] 220, the next year I might repeat [that test] and find that it's 150. There are other kinds of things that we will do, too. It's really all a part of a comprehensive plan.

In the survivor of cancer I'm looking for those kinds of things later, after the patient has been, presumably, cured of the cancer . . . in our office a lot of what I do is pretty much general medicine because it's [about] survivorship. It's [about caring for] the patient who has been successfully treated for cancer. There are some special things that we do. As we improve our treatments, there are more survivors; not only that, but also, people are living longer now. Median survival, [reported] the other day in *The New York Times*: 78. So our population is aging. Of course there are going to be more and more of [issues around survivorship], so we look for them, yes.

WOMAN:

I had my breast cancer on the left side. The first time I had a lumpectomy, and then the second time I had a mastectomy, but [both were performed] within three years [of each other]. I heard you say something about a massage. My daughter was going to take me for a full-body massage once, and they didn't want to do it because I had had breast cancer. Would that stimulate anything?

EDITH P. MITCHELL, MD, FACP:

For many [businesses], they won't do them because of liability. I do recommend relaxation and massage therapy, and there are special places you can go for that. Some [businesses] won't do

the therapy unless you have a doctor's prescription. So they're mainly concerned about liability, and you can understand that.

WOMAN:

Has tamoxifen been implicated in neuropathy? [I'm thinking of] someone who's been on the tamoxifen for five years and [who] maybe didn't have any symptoms then, but down the road maybe is showing something.

EDITH P. MITCHELL, MD, FACP:

Sure. Tamoxifen is low on the totem pole [in terms of] agents that cause neuropathy. If I look at all of the medicines that patients take — the most common complaint about tamoxifen [that I hear from my patients] is, "I feel good, and I eat too much, and I'm gaining weight." But there are a few patients who have complained of neuropathy from tamoxifen.

WOMAN:

Like trigger finger, would hammertoes be a symptom of ...

EDITH P. MITCHELL, MD, FACP:

Yes.

WOMAN:

It's hard to wear a shoe. [Inaudible]

EDITH P. MITCHELL, MD, FACP:

That's correct. And you have to be very careful about the type of shoe that you wear.

WOMAN:

When you say [to] tell your doctor . . . about the peripheral neuropathy, which doctor [do you mean]? Your oncologist? Your radiologist? Your primary care doctor? Who?

EDITH P. MITCHELL, MD, FACP:

Everybody, or anybody who will listen. All of them should be knowledgeable about it but, as you know, sometimes people listen in different ways. They communicate in different ways. Not everybody is a good listener. So talk to anybody who will listen to you.

WOMAN:

There was a woman over on the very end over there, and she spoke about her foot. I wanted to know: was . . . her foot [injured before] she had the neuropathy? I'm asking that question because I have a problem with my foot, and it was throwing me off balance. I think I had a mixture of that and neuropathy. I was wondering if that's what she was speaking about.

EDITH P. MITCHELL, MD, FACP:

She was saying she had an injury as a teenager and then other injuries plus the neuropathy from the chemotherapy and radiation. So there can be a mixture of problems. I showed you many things that can further accentuate the neuropathy, so it can be a combination of problems.

WOMAN:

[In my] left foot, the tendons — like, my arches and whatnot — have gone bad. That's what caused me to not have a good gait. I also am a cancer patient, and I have been taking Taxol. But I'm not taking it now. I've been off it for a year. But I do have these symptoms other than neuropathy, and that's why I'm here. At first, when the doctor was speaking to me about the numbness and the tingling, I wasn't having those at that point. But I'm having them now. I think it's all contributed — [I think that based on] listening to what you were saying about these different medications and how they can cause you to have these symptoms of neuropathy.

EDITH P. MITCHELL, MD, FACP:

That is correct. The neuropathy can occur long after the Taxol or other medication has ended.

WOMAN:

I was just wondering: You said sometimes massage can help and that sometimes you need a physician's script for it. If we get that script and go to a place such as — Broomall has a Lankenau [Hospital; <http://www.mainlinehealth.org/lh>] extension and they give massages; will that be paid for by Personal Choice or any of the ...

EDITH P. MITCHELL, MD, FACP:

I don't want to tell you for sure, but there are some conditions under which the insurance will cover it. It will depend on the situation. You want to make sure that you don't have osteoporosis or some other condition that the massage might worsen, so you want to ask your doctor if it is okay for you; whether or not you have osteopenia or osteoporosis, or any other condition that could possibly be worsened by the massage therapy. Depending on what the situation is, what the final diagnosis is, there are some conditions under which physical therapy and many of these techniques that I've described would be covered, yes. But it's not blanket coverage.

WOMAN:

I'm an 11-year survivor of inflammatory breast cancer. Shortly after my treatment I developed



severe constipation that lasted for many years, and the doctor said it might be a paralysis of a portion of my bowel. Could that be part of the neuropathy? And I am now being treated for gastroparesis. So are they both, maybe, ...

EDITH P. MITCHELL, MD, FACP:

They all are parts of neuropathies. That's why I showed the slide early on. It depends on the part of the body that is affected. If the internal organs are affected, there can be poor emptying of the bladder. There can be a slowed or decreased motility of the GI tract. There can be gastroparesis, which is a more severe form of neuropathy. There are some chemotherapy agents that are notorious for causing [gastroparesis.]

WOMAN:

So, therefore, the doctors don't know. They're really treating me for neuropathy.

EDITH P. MITCHELL, MD, FACP:

This is a new area of medicine, survivorship. That's why I say that [it's very important] to tell your congressmen [or congresswomen] to support the medicine, to support insurance coverage of survivorship evaluations. Many times ... [I've encountered an] insurance [company that] doesn't want to cover the patient seeing me after five, six years. So you've got to make sure that [your doctor is reporting] the diagnoses correctly. What you don't want your doctor to write is "history of." That [indicates] a no-coverage period. I don't mind saying "breast cancer surveillance." That usually gets it approved.

[I am comfortable saying that because] the longest time between mastectomy and metastatic disease that I've seen in a patient is 28 years. This lady presented with liver metastases, and I went back to her hospital, wrote a letter, asked if I could get the pathology [sample from] her breast cancer surgery 28 years earlier. Lo and behold, they still had the tissue. We compared them and [found that] it was the exact same cancer. So we do see 10-year recurrences, 15-year recurrences. Educate your physician. [Tell your doctor,] "Don't put 'history of.' Just write the diagnosis." If you're getting a test, have the doctor say "surveillance," which means that he or she is checking to see if it could be recurrent breast cancer.

WOMAN:

Epsom salts. Do they not also dry out ... I'm having total issues. I have 19 different creams that my friends have donated to my cause to try to

moisturize this condition that I have from my meds. I stopped using the Epsom salts, which I found very relaxing, because someone told me they actually dry you out. But if you use them for 15, 20 minutes and then add a cream, would that neutralize the drying effect?

EDITH P. MITCHELL, MD, FACP:

Sometimes just being in water, of course, can accentuate drying. What I do recommend is what [we did with] my great-grandmother: we would rub her feet with oil or some kind of moisturizer after the soaking ... I do recommend that you use some kind of moisturizer. That massage afterward can be very important, too.

WOMAN:

But you can do your own massage. Is that correct?

EDITH P. MITCHELL, MD, FACP:

Oh, yeah.

WOMAN:

Or do you have to have ... okay.

EDITH P. MITCHELL, MD, FACP:

No. I think any massage is better than no massage.

WOMAN:

Are there any exercises for the feet that you can do that would help?

EDITH P. MITCHELL, MD, FACP:

A rehabilitation specialist can help you with them, depending on the situation. For example, for some nerve damage there will then be loss of muscle and loss of muscle function; thinning of the muscle. The rehab specialist can help you with that, yes.

I think a rehab specialist is very important. There are some people in family medicine who do that [rehabilitation work] very well. Others, in orthopedics, do that very well. I really like to start with the oncologists and the rehab people, but there are some internists and some family physicians who do that extremely well.

WOMAN:

Where do you find good massage therapists or foot reflexologists that are actually certified?

EDITH P. MITCHELL, MD, FACP:

I don't know that there is a certification for that. But I think that there are multiple ways [to find a good one]. One is by word of mouth. So that if you [want to] go to some place in Bryn Mawr, [you will find that] many people will go to

[the same] place. The patients will tell me where they go and whether it was beneficial or not. Then the patients will tell each other. So I find that support groups, patient information groups, to be the best. To my knowledge, there is no certification except the state licensure and health department kinds of things to make sure that the facility is clean. But I think that most people can just put up a sign and say, "Massage for sale."

WOMAN:

There is a certification.

EDITH P. MITCHELL, MD, FACP:

There is a certification.

WOMAN:

[Inaudible] certified massage therapist. [Inaudible Portion]

EDITH P. MITCHELL, MD, FACP:

Sure, and I always look for good information from people. Some of my patients tell me good places to go. I always look to my rehab people to help me in giving recommendations to people. Another place is the Y [YMCA: <http://www.ymca.net>; YWCA: <http://www.ywca.org>]. I find the Y out here in Paoli to be very good. They've got a pool that they tell me is 85 degrees year-round and is very comfortable. But, again, talk with your doctor before you get involved in any major exercise program.

WOMAN:

I would agree that most doctors pass over neuropathy. They give you a very fast answer for it. If you take gabapentin, how long do you have to take it before it starts to take some effect?

EDITH P. MITCHELL, MD, FACP:

The question is [about] one of the medications, gabapentin — Neurontin is the brand name for it. I have no connections with any of the companies making [that medicine]. It depends on the dose that [patients] start with. Individuals who are chronologically blessed might have more symptoms from the large doses, so I usually start with a smaller dose and slowly increase it. It's usually about seven days before the patient notices any effect, and some patients will notice a maximal effect after two to three months of treatment, but a lot depends on the dose.

WOMAN:

Does neuropathy get worse at night? That's what I find. In bed.



EDITH P. MITCHELL, MD, FACP:

Yes, especially if the nerves to the skin are affected. Many people tell me that even the linens and the bed covers affect them and that the bed covers sometimes increase the pain. They will get up at night after going to bed because the pain is worse. That, of course, [results in the patient experiencing] sleep disturbance [in addition to the neuropathy].

WOMAN:

Do leg cramps come from neuropathy?

EDITH P. MITCHELL, MD, FACP:

They could. Leg cramps can come from other things, but yes, neuropathies can cause leg cramps.

WOMAN:

I was diagnosed with neuropathy a couple of weeks ago ... I guess my main question is about the diabetes. You were saying ... is there a special type, like [type 1 or type 2] diabetes, or doesn't it matter?

EDITH P. MITCHELL, MD, FACP:

No, it could be type 1 or type 2. And diabetes is the most common cause of neuropathy in the world. [If neuropathy is occurring for any other reason,] diabetes could make it worse.

WOMAN:

I just finished [bone] therapy. ... The oncologist said that I don't have to have any more treatments, thank God, for the next six months. But my glucose level had gone up, and they were saying [that] I have to really watch it, so that's why I was asking. The other question [I have is] about the potassium. I wasn't quite sure what you were speaking about [when you mentioned] low potassium. Is that a [inaudible]?

EDITH P. MITCHELL, MD, FACP:

A low potassium [level] can just accentuate the pain, accentuate the dysfunction from the neuropathy. Your doctor should check to make sure your potassium [level] is in the normal range. If, for example, you are on a thiazide-type diuretic for hypertension or heart disease, that can accentuate neuropathy.

WOMAN:

Right. Because the therapy that I did have — mainly the Herceptin — damaged my heart. That's why I'm on that.

EDITH P. MITCHELL, MD, FACP:

Yes. There could be multiple problems contributing to the effect.

MAN:

This is just a comment. I have very bad peripheral neuropathy as a result of diabetes. Gabapentin did absolutely nothing for me. We tried all kinds of treatments. Then Lyrica, which is pregabalin, did miracles. I was at the point where I was not able to go to a movie or a show because it would drive me crazy, and now I could do that without a problem.

EDITH P. MITCHELL, MD, FACP:

Every patient is different. I have some patients who tell me that Neurontin helps, others who say it doesn't and others who will have side effects from one or the other [Lyrica or Neurontin]. Neurontin, or gabapentin — it's one of the older drugs. Now there is Lyrica, which I call the new kid on the block. [It] gives us more options: if one medication [isn't] helpful for one patient, you've got other medications that might offer some options for treatment.

ELYSE S. CAPLAN, MA:

Just as you said, in terms of the cancer treatment arena, when you started [the presentation] with [information about] the NSABP's 50th anniversary — which I thought was a great overview and launch pad [for the rest of the talk] — you just brought light to the survivorship concerns and the medications that help treat the quality-of-life problems. Lyrica is the new kid on the block. So that type of medicine is also evolving and changing.

EDITH P. MITCHELL, MD, FACP:

Absolutely.

ELYSE S. CAPLAN, MA:

That's great.

EDITH P. MITCHELL, MD, FACP:

There are clinical trials [in which] patients can participate and get information on new drugs that might be coming down the pike. Sometimes we have to add [other medicines] to the Lyrica [to make it more effective.] Some patients might be on two different medicines.

ELYSE S. CAPLAN, MA:

I am going to officially wrap up the program and thank everyone.

EDITH P. MITCHELL, MD, FACP:

Thank you for the invitation. I've really enjoyed this. (Applause)

ELYSE S. CAPLAN, MA:

You will get more invitations. Trust me. Thank you, everyone, for your patience.

[END OF TRANSCRIPT]