



354 West Lancaster Avenue | Suite 224 | Haverford, PA 19041

Phone: (610) 645-4567

Fax: (610) 645-4573

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Getting Relief: Pain Management Strategies for Women Affected by Breast Cancer

March 26, 2008

Kathleen M. Foley, MD

OPERATOR:

I would like to welcome everyone to the Living Beyond Breast Cancer teleconference. It is now my pleasure to turn the floor over to your host, Elyse Caplan. Ma'am, you may begin your conference.

ELYSE S. CAPLAN, MA:

Thank you, and welcome, everyone, to Living Beyond Breast Cancer's teleconference, "Getting Relief: Pain Management Strategies for Women Affected by Breast Cancer." As many of you may know, I am Elyse Caplan. I am the education director at Living Beyond Breast Cancer, and I would like to welcome all of you. Today's topic is of great importance to us here at Living Beyond Breast Cancer, because our mission, which many of you know, is to empower all women affected by breast cancer to live as long as possible with the best quality of life. That is integrated into every program, service or publication we produce here. The quality of life is really at the fore of everything we do.

Managing pain, whether you're recently diagnosed, have had breast or reconstructive surgery, or if you had surgery many years ago, or if you're dealing with pain associated with treatment effects, both the short-term or acute effects and the longer-term or more chronic effects, we know this clearly affects your day-to-day living. Today's program will help address a number of methods that are available to help you effectively manage your pain. We do understand that in some cases it may take some time for your doctors to figure out the best method or combination of methods to help you live better. We do know that communicating your needs to your doctors and your nurses in an ongoing way will help you get the best care possible and become more comfortable, so make sure you keep talking with your health care team about the things that bother you.

During today's teleconference, you will hopefully find a better understanding of some of the research that's been done in the area of pain management so you can go back to your doctors and your team and ask questions that might apply to your individual situation. Our featured speaker today is Dr. Kathleen Foley of Memorial Sloan-Kettering Cancer Center, and she will share with us some practical ways to help you alleviate or reduce pain related to breast cancer and its treatment.

Moving on a little further, today's program will be interactive. There will be the opportunity for questions and answers following the presentation. Some of the things you'll learn about today are dealing with postmastectomy or pain associated with your lymph node removal, pain related to radiation therapy of the breast or other areas of the body, managing neuropathy or joint pain that might be associated with some of your medical treatments, and easing chronic pain or discomfort that may be part of life for women living with metastatic breast cancer. . . .

. . . I also want to encourage participants to keep in mind that LBBC's Survivors' Helpline [(888) 753-5222] is a peer support telephone service that can help you connect with other women who have been diagnosed with breast cancer who are happy to talk with you about some of your ongoing concerns, to provide that emotional support that is often helpful. On our website, we offer a number of message boards where you can pick a different forum to discuss some of the issues that are important to you and hear from others across the country and around the world who may also resonate with some of your worries or concerns or who can answer your questions. Please feel free to check out those services that we offer. . . . Feel free to share that with those who may not have been able to tune in today.

Moving on, I'd like to tell you about our speaker and then turn the floor over to Dr. Foley. Dr. Kathleen Foley is an attending neurologist in the pain and palliative care service at Memorial Sloan-Kettering Cancer Center and a professor of neurology, neuroscience and clinical pharmacology at Weill Medical College of Cornell University. Dr. Foley was the previous director of the World Health Organization Collaborating Center for Cancer Pain Research and Education at Memorial Sloan-Kettering. She also holds the chair of The Society of Memorial Sloan-Kettering Cancer Center in pain research.

In addition, Dr. Foley is the medical director of the Open Society Institute's International Palliative Care Initiative of the Network Public Health Program, working to advance palliative care globally. Her national and international efforts in the treatment of people with cancer pain were recognized when she was elected to the Institute of Medicine of the National Academy of Sciences. Without further delay, I am so pleased to welcome Dr. Foley to today's program.

KATHLEEN M. FOLEY, MD:

Thank you so much for the introduction, and I'm glad to be here to talk with all of you. What I thought would be most helpful is to have this first brief introduction and talk and then open it up to questions. One of the important issues in my experience, what I've learned from patients, has been the concern that they have about whether their pain can be controlled. This is something that probably was most historically presented to me when a woman with very advanced breast cancer came to see me complaining of pain really diffusively throughout her body secondary to metastatic disease and secondary to bone pain. Her greatest concern was that it couldn't be treated, it wouldn't be relieved, and that she would die in terrible pain. This concern had haunted her for weeks and



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weeks, and it had haunted her so that she couldn't even talk to her doctors about it or really advocate for herself.

As we opened up the discussion and looked to different approaches and what might be effective, she had clearly not had the opportunity of any of those approaches, and it made me reflect on the fact that here was someone who really could have had access to this information, but for reasons that I'm still not sure of, didn't have access to it or was so afraid to communicate about it that she was unable to utilize it, and lived with extraordinary fear. I think it's critically important, as much as you advocate for your own self for the appropriate treatment for your tumor, we need to advocate and you need to advocate for attention to and treatment of your pain. Maybe that attention and maybe those treatments may not be that successful, and we can talk about that, but it begins with first being able to communicate to your doctor about pain.

I want to spend a few minutes on that, because we're increasingly seeing that it's this communication issue around pain that often prevents patients from getting adequate treatment. Although women are usually good communicators and are usually good about voicing their opinions about their symptoms, it appears, from a variety of studies and from our own experience, that when you have a brief interlude with your oncologist, your focus is on what the treatment is doing. Is it effective? Is it showing that my tumor is reduced? Often those conversations are really short and truncated, and patients and women with breast cancer, to be specific, often don't bring up their pain issues with the physician.

When we've tried to explore why they may not bring those up, the first concern they've expressed is that they had such a limited amount of time, they wanted to focus on their chemotherapy regimen or their radiation therapy regimen, and they didn't want to spend time on their symptoms. Even the patient herself is not feeling adequate enough, strong enough to communicate that to the physician. If we don't communicate it, we clearly will never get it treated.

A second point that became very obvious to us in a variety of attempts at trying to improve the assessment of patients with pain is that in this issue of communication, often the patient felt better on that day and therefore minimized the pain, which might have been excruciating two days before or five days before. Only if there's a family member sitting in the room, who will be their advocate.

A second piece that we think is really important is for you to be able to have a plan if you have developed a new pain or have persistent pain that's not clear, to have a strategy when you go to see your physician about that pain. The strategy is for yourself reflecting on it because, remember, your oncologist is not a veterinarian. He's not going to be able to get this information without you being able to put it together.

We think getting prepared for how to communicate to your physician or the nurses providing care to you about your pain is the critical first step. It also facilitates the ability of both the nurse practitioner who may be following you and the physician following you to be able to come up with a therapeutic approach. In my mind, this is the most important thing to have to happen, and if it's not you who is able to do it, then maybe it's you with your family member, who could be your ombudsman to speak to it. You can even write it up and send it to your physician in advance. It comes up with the really simple questions that you need to ask yourself, and it begins with: Where is my pain, and when did it begin? Each of these questions is incredibly important, because they will help your doctor and the nurses caring for you to be able to define what your pain syndrome is, and we see that as a really important step.

It also helps to define whether this may have anything to do with your disease, with cancer, or is unrelated to your cancer. It's incredibly important, because it also helps to define when and how it began, and this is commonly the type of pain syndromes that occur following surgery, be it a sentinel node biopsy, be it an axillary dissection, be it a mastectomy, be it a lumpectomy. Being able to define the point in time when it began, when it may have become exacerbated, and then having a clear picture of what you've tried to be able to say what works or what doesn't work – it's where is the pain, what makes it better, what makes it worse, when did it start, what is it related to and your own issues related to that?

This became very important when we were beginning to define a series of syndromes in patients with breast cancer. We divided them into syndromes that are associated with direct tumor involvement, and the syndromes that are related to the therapy you received, and then syndromes that occur independent of your cancer or independent of your therapy. We all are at risk of developing low back pain or developing arthritis or developing acute abdominal pain related to a

GI obstruction unrelated to our cancer or anything else. These distinctions of and definition of specific pain syndromes help the clinician target a very specific approach and help you understand what's happening.

Probably the best of the examples is that early in my career I was seeing a large number of women who had significant burning pain in their chest wall, and these are women who, in those days – in the late '70s – had undergone simple mastectomies, more radical mastectomies. They were complaining of burning pain in the chest wall and in their axilla. We defined a syndrome called postmastectomy pain. This comes from selective interruption of the nerves that innervate the breast. It commonly occurs in women who have had more radical procedures than less radical procedures. There's some reason to believe that some patients in the general population, some women, are at more risk for developing this pain syndrome. We don't know what the attributes are, what genetic attributes confirm the cause of postmastectomy pain, but it seems that there might be some selective genetic group of individuals who develop this type of pain.

With that, this is a kind of pain that, in my experience, has never been associated with recurrence of disease. I've never seen it as a presentation of someone who had a recurrence of disease in their axilla or in their chest wall. It hasn't been associated with that. Making the distinction between a postmastectomy pain that comes from a surgical procedure on the breast or axilla as compared to tumor infiltration in that same area is critically important, because the treatments are very different. The treatments for tumor would be, obviously, changing your chemotherapy regimen or considering radiotherapy, where, in the setting of this being related to a surgical procedure, the focus is predominantly on pain.

I'm using that as one example where the history is so important in your ability to be able to help the clinician come to that kind of diagnosis. Not only do I need you to be able to define where your pain is – and what makes it better and what makes it worse and what treatments have been effective or what positions you get yourself into that maybe make you less painful, or what things you do make it less painful and what things you do make it more painful – but also to place it in the setting of your illness and be able to define what may be its cause. That's a first important aspect.



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The second important aspect in the conversation with your clinician and with the nurse is being able to just talk about the intensity of your pain. Again, this has been my own experience with patients: Some people won't even use the word "pain;" they want to use the word "discomfort." Pain is just not part of their language. It's not a word they use. It is a word we use to describe a physical pain. Again, importantly, being able to describe what that physical pain is like: Is it mild? Is it moderate or severe?

Now, because of the introduction by the Joint Commission of a scale and the need to report pain at every visit where a patient is seen, both in a hospital setting and in an outpatient setting, many institutions and many doctors use a variety of scales. One scale is called a visual analog scale, which has zero on one end – it's a line – and ten on the other. You mark that line and see how bad your pain is, with ten the worst pain possible and zero being no pain. Sometimes those scales may be just words: "mild," "moderate," "severe," "excruciating." Some groups are using faces for people who are not able to use language appropriately, and using happy/sad faces to identify the degree of pain.

There are these series of scales out there that can be used, and you may have participated in some studies using those scales, and they can be very helpful because they allow us to get information about the intensity of your pain. But another important element is to not only think about pain intensity but also to think about the relief. If you took two Tylenol before you went to the doctor and got complete relief, that's very useful information. Or, if you took two Tylenol every three hours for two days and got no relief, that's critically important information. Providing that kind of basic information to the clinician can be so helpful. You, yourself, are sort of experiencing it. What I'm asking you to is to attend to your pain and attend to your symptoms so that those kinds of information can be provided to the clinician.

A third component is to be able to – if you're not so good at defining its intensity or defining the degree of relief that you're obtaining – describe how the pain interferes with your daily activities. There is a scale that we commonly use, and you may have participated in this type of an exercise at your clinician's office. It's called the Brief Pain Inventory. Many clinicians, many oncologists are using this in routine practice, where you talk about not only the intensity of pain and your degree of relief, but also how the pain interferes with your

functional activities: your ability to sleep, to walk, to dress yourself, to interact socially. What we know about the persistence of pain is it basically wears away at your personality. It demoralizes you, and it can even lead to depressing you. It clearly demoralizes you and makes you unable to do your normal activities. As you're unable to do your normal activities, it then forces you to withdraw.

Because no one can see your pain, they can only hear your reports of your pain, and because your reports of pain are subjective to you, it's very, very hard for people to say, "Well, you don't look like you're in pain." One of the important facts we've learned about pain is it has two types: what's called acute pain and what's called chronic pain. Acute pain is an episode of pain that comes on typically – postoperative pain would be an example, or if you fell and sprained your ankle and had the onset of acute pain, or if you burned your finger. All of those would be episodes of acute pain, which can increase in intensity initially and then slowly decrease in intensity and go away. We call acute pain this pain that lasts for a few days to a week.

Chronic pain is pain that lasts longer than three months. There is good evidence to suggest that when you have acute pain, your autonomic nervous system is very highly reactive and you look like you're in pain and can be moaning or groaning. If it's severe and excruciating pain, you can also develop a very rapid heart rate, and your blood pressure can become elevated. People with chronic pain don't look like they're in pain. They're not sweating; they're not moaning and groaning. Their blood pressure is stable. Their pulse rate is stable. But they're reporting to the physician that they're in terrible, excruciating pain. This mismatch – clinicians looking at patients like that have difficulty believing it and understanding it. That's why it is so important to be able to define clearly for your clinician and healthcare professionals who are providing care, as well as for your family, what the other elements of the pain are so it paints a full picture of who you are with pain.

Having given you a very short summary of how to communicate to your healthcare professionals about your pain, the second piece of it is what you should expect from them back. What would we want [from] them, and how would they approach your pain? One of the difficulties in this assessment of pain – and we spend a great deal of time in the pain assessment piece – is asking patients and asking you to think about, "What's the meaning of pain to me?" Is the meaning of the

pain to you that this terrible back pain I'm having must be because I have new metastatic disease? That has enormous psychological consequences to you and enormous impact on the status of your disease and what treatment you'll have.

It also means that in presenting that information to your clinician, they may be changing the approaches or they may suggest other approaches or they may suggest that you get further radiologic studies. The meaning of the pain to you is critically important, because it will make you be more concerned that your illness is now moved from very early-stage disease to more advanced disease, and it brings on all of the concerns that you have. The psychological issues that are critically important for you, and your social issues and your worry about the future all come into play.

There is clearly heightened intensity over the pain at that point in time, and there is no question that that degree of anxiety and that degree of demoralization can heighten your pain symptoms, so there becomes this vicious cycle. These are important elements for you to think about so you can begin to express them to your physicians and say, "Do you think this is new disease or metastatic disease?" Then understand what will be the process for the physician to sort this out.

What we've also seen – and we are not sure how to deal with this except to tell you about it as a phenomenon that occurs and an experience that patients have – is that patients with very advanced disease who are receiving chemotherapy from their clinicians are often hesitant to say they have a new pain, and they're often hesitant to talk about new symptoms they might have, because they don't want their doctor to give up the treatments they're giving. They don't want their doctor to think the treatments they're receiving are failing. That is another piece of how you report pain that influences the situation around you.

Lastly, there is clearly significant pain that could occur in patients who have very advanced illness. At this point in time, the information we have on general populations, but patients with cancer, specifically in the breast cancer population, is that about one-third of patients can have some type of pain in active therapy, and about two-thirds of patients with very advanced illness can have pain. The good news is that more than 95 percent to 97 percent of those patients with advanced illness can obtain relief by the wide variety of approaches that are out there that are not simply focused on the pain but are also focused on



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improving their disease. Radiation therapy can be an incredibly useful and positive analgesic treatment because it can rapidly reduce the pain associated with metastatic bone disease.

The good news, again, is that although metastatic bone disease had been the most common cause of pain in women with breast cancer, we're now seeing a marked reduction in that symptom because of the variety of new approaches and the use of bisphosphonates, which remain controversial at this time, in preventing the development of metastatic disease or further progression of bony disease. The newer treatments that we have are, in fact, changing the pain syndromes we're seeing in patients with advanced cancer, and they're also changing how we think about the treatment approaches. What I've tried to do is summarize the big overview picture, and now I want to spend a bit of time on the various treatments that are available.

When we talk about treatments, again, we want very much to rely on what we are calling this pain syndrome. These pain syndromes – we doctors define them into different types, and we call them somatic pain syndromes and neuropathic pain syndromes. Why is this important for you to know? A somatic pain syndrome would be a pain syndrome that involves, for example, bone or the soft tissue, whereas a neuropathic pain syndrome is a pain syndrome that results from injury to either the peripheral nervous system – it could be a peripheral neuropathy – or an individual nerve that occurs in axillary dissection or a mastectomy, or it could involve more central processes like the spinal cord.

We make these distinctions because it appears that the mechanisms of bone pain are different from the mechanisms of neuropathic pain, and we have, perhaps, better treatments for bone pain than we have for nerve injury pain. We need to approach the patients and their treatment based on the mechanism of pain that's happening.

Having defined what the pain syndrome is, and then defining what we call the different types of pain mechanisms, we come up with a therapeutic approach. The mainstay of treatment of cancer pain has been the use of a range of different pharmaceutical agents, anywhere from a simple Tylenol or ibuprofen or Advil, to opioids for moderate pain – that would be a drug like tramadol; it's called Ultram on the market and has a bit of an opioid and other drugs in it – to oxycodone or codeine or Vicodin, to a third class

of drugs like morphine, hydromorphone and methadone. I don't expect you to know these drugs or their names; just pointing out that there are different classes of drugs that are effective based on the intensity of pain.

Drugs like morphine, which has been the gold standard drug for treating severe pain, are the drugs most commonly used for moderate to severe pain and specifically for severe pain. Morphine is currently available in a range of different preparations – what are called immediate-release tablets that work for every four hours, and slow-release tablets that work for 12 hours or 24 hours. The other drugs that are available in the class of drugs for severe pain are patches; the use of what's called Fentanyl patches for patients with severe pain can provide 24-hour relief.

The importance of this general use of analgesic drugs is the fact that they can be effective for mild pain, for moderate pain, for severe pain. We choose the drugs tailored to the individual patient, and we're coming to increasingly recognize that just as we're targeting chemotherapy for a specific genetic makeup of patients, we're seeing this is also the case in the use of opioid drugs. We're seeing that of 100 patients that might take morphine, about 25 don't do well on that drug and need to be switched to another drug because of their certain genetic makeup, which alters how they metabolize the drug. We're understanding how we need to provide targeted analgesic treatment for patients based on their genetic makeup in the same way that we're looking at targeted therapy for breast cancer based on your receptor status.

The important aspect is that there is a wide range of drugs, so if one is not effective, we can rotate you to a second drug or a third drug. Again, our experience, in a study that we did here at Memorial, was that some patients – this was clearly patients who were in hospital, who had more advanced disease – we often had to rotate to a second or a third drug before we were able to provide them with really adequate relief. The important part is that we were able to successfully give them good treatment approaches. The good news is that we know how to do these treatments, we can rotate the drugs, and that provides a patient with a better opportunity for pain relief.

What is our goal in all of the management of pain? One of the great concerns that patients have and that you, I'm sure, have expressed to your doctors, is: "I don't want to take these drugs because I don't like how I feel. They may make me

sleepy." Again, with careful titration, we've been able to work out regimens for patients that allow them to function as they need to function, to be able to take care of their children, to be able to go to work if they work, to be able to teach school if they teach school, and to be able to still obtain adequate relief. This is emphasizing the need to maximize their pain relief and also control any side effects. There also is a negative aspect to these drugs that you clearly have been witness to in our own society, and that is that these drugs, because they are opioids, run the risk of making you dependent on them and there's a concern that you might become an addict.

If you take strong opioids on a regular basis, you will become what's called physically dependent on them, and that means you just can't suddenly stop taking them. If you do that, you'll develop symptoms and signs of what's called withdrawal. You'll feel achy and nauseated, and you may have diarrhea. It's not more serious than that, but it's not a good feeling. Our experience is that we use these drugs to be able to give you enough relief to be able to get you through the treatments that you need – the idea of taking medication when you have acute, severe pain, let's say, and then are getting adequate radiation therapy, and when your radiation therapy is over, you may no longer need to take any of these medicines. My own experience is, with patients receiving radiotherapy or chemotherapy, they may have the onset of an acute to almost subacute pain syndrome, they take pain medicines for several weeks, and then they taper off and no longer take them. Again, we've been able to demonstrate this clearly.

We see the use of these drugs as the ability to provide the patients with improved function and improved access to the appropriate treatments. If you're in terrible pain, you can't begin to get out of your house, into a car and out of your car, into a hospital to get your radiation therapy, or to the doctor's office. It's getting control of the pain and then getting the appropriate treatment for your cancer. We see these totally wedded to each other and not separated. Therefore, the mainstay of drugs is – typically a patient might try, if they had mild pain, to take simply Tylenol. But there is a limit to the amount of Tylenol you can take. Or they might simply take some oxycodone or hydrocodone, which is Vicodin, or they may be on morphine. Then they'd be effectively treated for whatever the cause of the pain was, and they'd taper off their drugs. That's a large population.



There are then patients who have more advanced illness and more advanced disease in which they may take their medications for several weeks or months at a time. In that group of patients, what we're always attempting to do is fine-tune their medications to be able to, again, maximize their pain relief and minimize their side effects. Along with what are called the non-opioids, like Tylenol or acetaminophen, and the opioids like morphine, fentanyl or hydromorphone, there is a third class of drugs called adjuvant drugs. These adjuvant drugs can improve pain, provide analgesia, but work by different mechanisms. In patients with neuropathic pain, the common drugs that are used are Neurontin or gabapentin that work selectively on neuropathic pain, or drugs like antidepressants that, in set doses, can be very effective. These are some of the common antidepressants that we've used and some newer ones that are on the market.

What we've attempted to try to put together is a combination of different drugs to be able to provide you with good relief, manage your side effects and keep you functioning. If any of these drugs are making you nonfunctional, then they're not the right drug for you, and we need to come up with a better strategy for you. Drugs are one big group of approaches. A second group of approaches that we think are very important are a wide variety of psychological approaches, cognitive-behavioral approaches, to provide you with relaxation and with distraction and to use these, again, in combination with your analgesic drugs. Some patients benefit from acupuncture. Some patients benefit from relaxation techniques. Some benefit from distraction. Some use hypnosis.

We don't in any way want to be critical about how each one of those may work for an individual patient. The difficulty is that the studies looking at the effectiveness of those approaches are fraught with errors in how to do the studies and maybe it's not even possible to come up with an evidence base. At least our experience here at Memorial is to be able to allow patients access to these various approaches to see to what extent they might benefit patients. There are also anesthetic and neurosurgical approaches, and I'm not going to spend much time on those, only to suggest that we have those and we use them probably less than 5 percent of the time, most typically in patients with very advanced illness.

One of the big questions that comes up for patients is their concern about when they would use and take these medications. One concern, they would say, "I don't want to take the medication now, because my pain is only mild or moderate. What am I going to do if it's really severe and the drugs won't work?" This is patients expressing a concern that they may become tolerant to the analgesic effects of the drug. It is important to recognize that we've been able to demonstrate in patients that we don't see a limit to tolerance, and we can increase the drug and continue to provide adequate relief. A second concern is that the drugs are associated with significant constipation, and how you moderate that effect. Again, we've come up with good approaches to prevent or reduce constipation.

The third concern is that, in taking the medications, somehow or another these medications may make the disease worse rather than better or might obscure any new problem that's developing. Again, this has not been the experience that we've had. Lastly, although addiction has been reported in patients with chronic nonmalignant pain in the general population, it's very rare, and it's even rare in cancer patients. It's just not something we witness. Our common experience is that patients take these drugs as they need them. When they no longer need them, they taper off of them and use them only to be able to control their pain, and they don't use them for other psychological support or for other behavioral reasons. We have the opportunity to have seen thousands of patients treated with these drugs and to see that they do play a role.

Coming back to the next big issue, and then I think I'll stop, is how you place pain treatment into your treatment for cancer. I clearly work at a major cancer center and work closely with our medical oncologists, and I think your pain treatment should be fully integrated. I have put a lot of demand on medical oncologists that they know and should know a great deal about pain management and be able to provide at least the first steps in management, unless you have a more sophisticated problem. If you have a more sophisticated problem, then you might need to be seen in the specialized pain clinic or in a pain and palliative care program. But I think that inherent in the treatment of patients with cancer should be the expertise of our medical oncologists who know how to assess and treat your pain. I think they should be the first place you go to ask questions

and to look for treatment, and they should be totally informed and a partner in your approaches and in your attempts to get good treatment.

In no way do I ever want to go around the medical oncologists. I want them integral to the treatment, and, similarly, there is enormous expertise in the nurse practitioners who work in cancer – both advanced practice nurses and nurse practitioners who have been adequately educated in appropriate pain management. Within that framework, then, often that would be the focal point for you receiving adequate treatment and having discussions, and then getting second and third opinions only if your needs had not been addressed by your medical oncologist and had not been able to be provided by your medical oncologist.

In all of this, there still are tough pain syndromes. These include the neuropathic pain syndromes. The peripheral neuropathy that occurs with chemotherapy typically gets better over time, and the most common drugs that we use to treat it include Neurontin or antidepressants. They work 50 percent of the time in 50 percent of the people. We need much better treatments for neuropathic pain than we have now. I think they represent the greatest challenges to patients with breast cancer. Secondly, another important challenge is the interface of anticipating your pain throughout the course of your illness and your concern and fear about pain.

To the extent that you have and are frightened about pain in your illness, it is really important to be able to communicate this to your clinicians so they understand that and anticipate and, in a way, prevent your pain, as opposed to waiting until it happens and then attempting to treat it. In all of the approaches we have, we want to stay on top of the pain. We want to stay ahead of the pain. This is why we want you taking your medications on a regular basis, not an irregular basis. We're focused on keeping your quality of living the best it can be, given that you have the pain syndrome.

Let me, I think, stop at this point. I'm glad to elaborate on any of these other aspects, but I think it's about time that we could open up to questions and hear your concerns.

ELYSE S. CAPLAN, MA:

Dr. Foley, thank you for covering in approximately a half-hour a lot of information. I'll recap a couple of highlights that I took away that I'm hoping some of our listeners did. I



appreciate you starting the program talking about communication around pain, because we definitely hear at Living Beyond Breast Cancer that that is something we need to do better, and women need to bring their pain concerns to their doctors and nurses sooner versus later, so as you said, a strategy can be developed. People need to develop that strategy before they even go to the doctor's office or make that phone call. If they need help, then getting a friend or family member to help them, or writing it down, whatever way can best communicate their concerns will be the very beginning of treatment being figured out.

I also appreciated you talking about and distinguishing the different pain syndromes, the somatic from the neuropathic, and the differences of acute versus chronic pain and the intensity and how that's treated in different ways. I also appreciated your talking about concerns regarding dependence on medicines and distinguishing the difference in becoming physically dependent, which is different from being addicted and relates to how one stops or tapers off of a medicine. One question I have before we turn it over to the operator to get everyone else's questions is two things.

Can you tell us, if someone is seeking a pain management specialist, is there a particular resource that is helpful? Beyond just going to your medical oncologist and asking for a referral, is there a particular resource that you can let us know about that can help women find a pain specialist? And do you tend to see in women, even with early-stage breast cancer who may be on aromatase inhibitors or other chemotherapy medicines, neuropathy and joint pain that is of the most severe type, where the common analgesics such as Tylenol or ibuprofen aren't proving to be helpful?

KATHLEEN M. FOLEY, MD:

Thanks for those questions. About the pain specialist issues: A foundation called the American Pain Foundation has tried to help patients with pain find the appropriate treatment people. They have a website [<http://www.painfoundation.org>] with information on accessing pain groups in various states around the country. There are problems with being able to list all of them, but at least they want to serve as a resource for patients in getting to the right pain specialist. There is also an Alliance of Cancer Pain Initiatives, and now it's become the Alliance of State Pain Initiatives. Their website [<http://aspi.wisc.edu>] is listed within the

American Pain Foundation. At each state, you can go in and find out who's working on cancer pain within your state. There are many regional state groups around the country that are quite effective in being able to advocate at a state level to assure that patients have access.

There is a specialty of pain medicine. Most typically the people who are specialized are anesthesiologists and neurologists, and they would be board certified by their specialty with a certification in pain management. When you're looking and questioning the credentials of physicians you're seeing, you want to be sure they are accredited in this kind of way and that they have that specialty. Within the cancer arena, there are many palliative care programs where pain is a major symptom they treat. Again, there is a specialty of palliative medicine, and there is an American Academy of Hospice and Palliative Medicine that has led the development of this new specialty. It's leading to a larger, expanded number of physicians with expertise in pain management for cancer patients. Those are two good resources to look at for pain specialists.

Now, back to the aromatase inhibitors: What has been reported is that there are a variety of syndromes that patients taking AIs can develop, and it's not clear why they develop them. Joint pain has been quite common. What is in the literature and in my own experience is that most patients are given Tylenol or some low doses of – their pain has been predominantly from mild to moderate. In those patients whose pain has been so difficult to control or severe, it often has been suggested that they go off the drug and have a holiday, and then reintroduce the drug to see if the joint pain, one, goes away, and then recurs, to be able to distinguish it from the development of rheumatoid arthritis or some other type of arthritic condition.

There's no question that joint pain has been reported. It has tended to be in the mild to moderate level. It has tended to get better over time. But there clearly are patients who have dropped out of studies and dropped out of treatment because the drugs have given them such significant joint pain. It's not clear what the full mechanism of that joint pain is.

ELYSE S. CAPLAN, MA:

Thanks so much for clarifying that; I do appreciate it. We do hear that it's fewer women who have the most severe pain associated with this, but those who have it have it 100 percent.

KATHLEEN M. FOLEY, MD:

That's correct.

ELYSE S. CAPLAN, MA:

They're struggling to find an effective way to live their lives in a more comfortable way.

KATHLEEN M. FOLEY, MD:

Let me add to that. There are, I think, a series of clinical trials that are going to look at that population and look at drugs that have been effective in neuropathic pain. There is awareness on the part of the pharmaceutical companies probably more than anyone else at this point of what population this represents. What I'm impressed with is that, one, we don't understand the mechanism fully, so there needs to be more research on this. This is a really important question. Two, we need a better handle on how many women this is happening with and on being able to distinguish it very clearly and carefully from the onset of some rheumatologic disorder. That becomes an important distinction – not simply say, "Well, it's just the aromatase inhibitors," but to make sure it isn't related to some rheumatologic disorder.

ELYSE S. CAPLAN, MA:

I appreciate you clarifying that. I know that's something we say from time to time, and I appreciate you saying that. There will be a series of trials that will be looking at this, and I think that gives us some hope that down the road a bit, hopefully, we'll have a better understanding, as you said, of the mechanism and why this happens to some people and not others.

KATHLEEN M. FOLEY, MD:

Exactly. It's a very important issue.

OPERATOR:

Your first question is from Montgomery.

CALLER:

Hello. I have neuropathy, which is worse in my toes and in the bottom of my feet, which makes it sometimes uncomfortable for me to walk. It's more discomfort than pain; you're right. But every now and then, I do get a pain shooting up my leg. I went to a neurologist, and she suggested physical therapy. I'm just wondering: Would that help? Because I did have acupuncture, and I got Lyme disease, and it set me back. I just wondered, would Neurontin help me, too? I heard you talk about that, and that was not mentioned. She had mentioned the antidepressants, which I didn't want to take, do not wish to take. But would that help also? I thank you for that.



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KATHLEEN M. FOLEY, MD:

The question we have is this question of what's the best treatment for neuropathy. You've been seen, and someone has diagnosed your neuropathy. I'm going to keep harping on making sure people get an evaluation and have a clear definition of what and why you have neuropathy and know what it is related to, i.e., was it related to the treatment you received? Or, there is a large population of people who develop what's called an idiopathic neuropathy. This can happen to you independent of ever having cancer and independent of ever getting chemotherapy.

With that in mind, in a series of consensus documents and guidelines that have been put forth, the best evidence we have is drugs like Neurontin – gabapentin is the generic name – and antidepressants. These are the most effective treatments. When one looks at the number of people who obtain relief, as I said, about 50 percent of patients can get up to 50 percent relief. That's what the biggest studies show. Would it work in an individual patient? I'm not sure. But typically that would be the first medication a clinician would offer to a patient with neuropathy. It may suppress these episodes of spontaneous pain that flicker up your leg or spontaneous pains that occur in the toes and feet.

Right now, the strategy is the first-line drug called gabapentin, or Neurontin. In our experience, we use a fair degree and a fair number of antidepressants in relatively low doses, because patients obtain relief in low doses. Again, it's time-limited. Neuropathic pain should get better if it's related to chemotherapy, but it may take weeks or months before it's better. The important question is whether physical therapy helps or hinders. The degree to which physical therapy can be helpful is only that it gives better ways to keep active and to continue to use your feet and use your toes and keep them strong, but it may not be particularly effective for neuropathic peripheral neuropathy alone.

CALLER:

Thank you.

OPERATOR:

Thank you. Your next question is from Austin, Texas.

CALLER:

Thank you. I have two questions, quick ones. Is it more common to develop a soft tissue injury in your hand around the area where you have the joint pain from the aromatase inhibitors or not?

In other words, is there kind of a weakness associated? Do you anticipate that going away in five years, when I stop taking the drug? The second question quickly is about post-bilateral mastectomy and then post-lymph node removal under my arm. I have kind of a chronic pain on the bottom of my arm. I'm not sure if that's a tissue or a scar tissue issue or a lymphedema issue. Thank you.

KATHLEEN M. FOLEY, MD:

The question of the soft tissue injury related to the joint pain: Again, I've just recently been reviewing this literature on joint pain related to aromatase inhibitors, and I haven't seen that come up as a question. I don't have reason to believe that you're any more susceptible to soft tissue injury or less because you're on an aromatase inhibitor, nor do I think it should then persist. Again, I will always emphasize the point that if you do have some focal joint pain or focal soft tissue injury in your hand that has limited you, it's really helpful to be seen by someone who is an expert on hands, be it a physical medicine doctor, a neurologist, an orthopedist or even a rheumatologist. Those are typically the specialists. Often times they have very specific approaches to managing a specific injury in the hand, so you might benefit from some of that expertise.

As it relates to pain under the arm: What we know is that after surgery, after any bilateral mastectomies or axillary dissections that a nerve called the intercostal brachial nerve is interrupted in – it is a nerve that typically would innervate the breast but sends a branch down the posterior aspect of the arm – often times you may have pain in the area of your triceps muscle, down the posterior aspect of your arm, above the elbow, and across the chest wall. That area can commonly be numb or burning. That is called a postsurgical pain syndrome. It comes from interruption of the nerve. It can be exacerbated at different times and get better at different times. Women often will complain that it's better for weeks at a time, and then it becomes acutely exacerbated. This is a type of neuropathic pain.

The good news is that it has never been a harbinger of anything more than having had the surgery, and it doesn't mean there's disease there or that you'll ever get more disease. It is a persistent reminder that you've had this procedure, though, and it can fluctuate with weather. It can fluctuate with anxiety. It can fluctuate with activity. It is neuropathic in quality.

ELYSE S. CAPLAN, MA:

Thanks, Dr. Foley.

OPERATOR:

Thank you. Your next question is from Bridgeport, Connecticut.

CALLER:

I want to ask another question about aromatase inhibitors. I was diagnosed with rheumatoid arthritis. I'm currently on tamoxifen, and I am told that within two or three years, we might get switched to Arimidex, and I'm really concerned over that. Do you have any ideas about this issue?

KATHLEEN M. FOLEY, MD:

I don't think there has been any evidence to suggest that it would exacerbate your rheumatoid arthritis. It's very possible that you might not have any joint pain. I think, if it's indicated for the treatment or prospectively for the management of your disease, it would seem to me very wise for you to start on it and see if you developed any worsening symptoms. There isn't any evidence in the literature to suggest that someone with rheumatoid arthritis is more likely to develop these symptoms. It appears to be independent of that.

The second point I'd like to also make is that's a couple of years off [for you to switch to the aromatase inhibitor], and my hope is that we might understand this mechanism better and the relationship to these other rheumatologic disorders. I think time is on your side. I don't think there's any reason to think you would not be a candidate or, at this point in time, that there's information to say you shouldn't be a candidate. It might require a trial to do it, but there are not patients who, on aromatase inhibitors, developed rheumatoid arthritis. That hasn't happened. They develop joint pain, but they don't have all of the markers that go with a clear definition of rheumatoid arthritis.

When some women have developed rheumatoid arthritis, it's thought to be independent of this. I have a patient I'm following who has lung cancer who has developed rheumatoid arthritis thought to be related to chemotherapy she received. But it was not an aromatase inhibitor. It was not any of those that you typically see with breast cancer. There is this phenomenon out there that patients with cancer are at risk to develop some rheumatologic disorders. But people with rheumatoid arthritis, going forward, do we think they're at higher risk for joint pain [while on an aromatase inhibitor]? No.



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CALLER:

Thank you very much.

ELYSE S. CAPLAN, MA:

I think that's really helpful, and I'm glad that question came up, because, again, we hear a lot from folks who have arthritis who are concerned about even starting an aromatase inhibitor.

OPERATOR:

Thank you. Your next question is from Malvern, Pennsylvania.

CALLER:

Thank you very much. I have lymphedema in my right arm following a lumpectomy. The pain that I have is more in the forearm. I appreciate what you said on the upper arm, but often what happens is from the swelling and such. What do you suggest for that type of pain?

KATHLEEN M. FOLEY, MD:

I think our understanding is that swelling that occurs is compressing both on the muscle and somewhat on the nerve and creating this sort of tight space. Probably the best treatment is trying to keep the lymphoma down as best we can with approaches that you probably are using — using a stocking and using exercise and keeping your arm elevated and keeping you from getting infections in your hand, and all sorts of things like that. Short of that, I don't think we have really good other approaches, to be very honest. We don't have any trials of using a drug like, let's say, Neurontin or gabapentin in that kind of setting to be able to say that might be of some benefit. Many of the approaches have been very much sort of mechanically addressed.

I guess, again, this is an example of carefully evaluating your forearm and your hand and making sure that's what the problem is and that you haven't developed another type of nerve entrapment that can occur, independent even of your lymphedema. Assuming that it's just lymphedema, these are the approaches we've typically used and often then come up to a wall. I think carefully assessing that you don't have any entrapment of a nerve there — does it occur more likely in certain positions, or could you say that?

CALLER:

No. It is only since the lymphedema and such. If the arm swells more, then it's more painful.

KATHLEEN M. FOLEY, MD:

It's more painful. There is no question that that would make sense, because what we're doing is distending the blood vessels there. We're putting pressure on muscle, and we're putting pressure on nerve. All of that would do that. That's why the whole approach is trying to keep the swelling down, because there are receptors in your forearm, or in your body in general, that respond to stretch. When they start getting stretched, they start feeling increased. They start firing. They fire into your nervous system and will fire in a way of reporting that there is some discomfort, that there is pain occurring. They are clear stretch receptors.

ELYSE S. CAPLAN, MA:

Dr. Foley, would you say that in some cases, as it relates to lymphedema, pain assessment management, the whole nine yards, that sometimes getting to a trained physiatrist or physical medicine specialist can really be helpful at the assessment of lymphedema or arm edema?

KATHLEEN M. FOLEY, MD:

Yes, absolutely. I think we have a lymphedema clinic here, and many places have developed lymphedema clinics. I think they're helpful because you have the opportunity to talk to clinicians — nurses and physical therapists and physiatrists and pain specialists — in that kind of setting, who have talked to a lot of patients and who have figured out other approaches that may be helpful or who have learned from other patients. Some patients say, "If my arm starts swelling up and if I go into a really cold room, I can get the swelling down significantly, or if I put it in these positions or if I do these exercises." There is a lot of common knowledge that isn't widely disseminated as much as we'd like, to be able to help patients.

Using those networks can be very helpful to get the sort of next level. Again, I wouldn't say there is a fair amount on the Internet, but there is a good amount on it. I would also say that this is not something your general practitioner knows. This isn't something that even your medical oncologist necessarily has a lot of expertise in, and they refer you on. Gaining as much expertise and talking to other patients about what they've used and what they've tried is enormously helpful.

ELYSE S. CAPLAN, MA:

Thank you.

KATHLEEN M. FOLEY, MD:

I don't want to diminish my clinician friends, but the reality is that we don't know everything, and there is a lot of good information that's widely available that we need to probably make better access to.

ELYSE S. CAPLAN, MA:

I agree with that.

OPERATOR:

Thank you. Your next question is from Indianapolis, Indiana.

CALLER:

Most of my questions were answered about the lymphedema, but have you seen that patients will use a topical cream on the arm? Has that worked, or have you ever recommended something like that just for some of the mild or acute kind of pain associated with that?

KATHLEEN M. FOLEY, MD:

There is an increasingly greater attention to the use of topical agents, and I'm glad you brought that up. For example, if you have some degree of nerve injury — I was talking about, let's say, in postmastectomy pain. We can sometimes see this across the chest wall where, if you've had a thoracotomy or a chest tube inserted, you can develop pain. It's burning, and it's dysesthetic. The area, when you touch it, is more painful. We call that term "allodynia." If you've ever had acute herpes zoster and then developed pain that persisted after the shingles or herpes zoster, the pain is also of this type, where you just touch the area that's numb, and yet it's very painful and very uncomfortable and you don't want anything against it. People with peripheral neuropathy also complain of this kind of sensation.

In those settings, the use of a topical lidocaine — there are now topical lidocaine patches, or a cream called EMLA, both of which have been reported to be effective. In fact, in a controlled study, the lidocaine patch was demonstrated to be quite effective. I do have patients who, in the setting of wanting to provide some topical relief, have used a topical, local anesthetic in an area where they've had some injury to their nerves. Also, patients who have just a focal, deep, aching pain have used local heat patches or local aspirin patches and have reported some success. There is a great deal of research going on looking at what could be the effective use of these topical agents. I don't think it's unreasonable to try one of these local



anesthetic creams. The last person we talked to, about this pain in the forearm, one could try it in the forearm to see if that made a difference. Or try it on an area of local pain to see if it's effective. At least in some patients, it has been reported to be effective.

CALLER:

Okay, thank you.

OPERATOR:

Thank you. Your next question is from [Inaudible], California.

CALLER:

I am calling about my daughter, who is 30, has metastatic cancer, is now going through Taxol and gemcitabine treatment and has a fair amount of neuropathy. I wondered if, besides taking things like Tylenol and Celebrex and stuff, are there any specific things she can do? She's very active, but when she's in pain, it's quite hard. I wondered if you could comment on that.

KATHLEEN M. FOLEY, MD:

Sure. Again, Taxol is known to create and produce a peripheral neuropathy. It appears to be dose dependent. It will get worse over the treatment course of the Taxol, and then once the drug is stopped, it will slowly get better – but it will take up to six or eight months to be better. The good news is that, ideally, she should be better when her Taxol treatments have stopped. However, the drug that has been demonstrated to be as effective as anything is Neurontin, or gabapentin. It comes in 100-milligram and 300-milligram doses. The dose that most patients need to obtain relief is about 900 milligrams. It's a safe drug. It doesn't interact with any of the chemotherapeutic agents. It doesn't have any negative effect on the GI tract or the liver or the kidneys. In a way, it's safer than Tylenol or Celebrex. It works in some patients.

It's probably reasonable for her to consider a trial of that. If that's not effective, there's a second drug on the market that is like gabapentin but a little different, and that would be a second kind of trial. Thirdly, a drug we've used longer than we've ever used gabapentin is relatively low doses of amitriptyline or nortriptyline, which is an antidepressant. I think patients think, "I'm not going to take an antidepressant, and it must be bad for me," etcetera. But these doses are relatively low, and they often can be quite helpful. Those would be the two different drug groups that I would think she might be a candidate for, and she could

talk with her doctor about trying them. Then she could benefit from knowing whether or not they were helpful.

CALLER:

Thank you.

ELYSE S. CAPLAN, MA:

Take care.

OPERATOR:

Thank you. Your next question is from Ann Arbor, Michigan.

CALLER:

Hi. I'm calling because I've had postmastectomy pain for three years, and I'm lucky I'm at an academic medical center. I've tried all of the things you've recommended, all of the drugs. I've also been to pain specialists and physical medicine specialists. I have still not gotten adequate relief. I'm wondering if I've hit the wall and need to go outside my state to look for treatment, and if you might recommend where in the country I might look for treatment of postmastectomy pain.

KATHLEEN M. FOLEY, MD:

You're not alone. I have patients who have gone through a whole range of different treatments, and still I don't think anything we've provided them with has given them much more than 30 percent or 40 percent relief, if even that, at different times. Yet, at the same time, I've seen people's pain get better for reasons that I don't understand, at three years, at four years, at five years. I don't even want to say you'll never be better, because I have a couple of patients for whom it took about three or four years, and they slowly were better. I don't think, at this point, there is any great center that you might [have benefited more from than] Michigan, because they have pretty good, smart pain specialists there, as well as really good breast cancer groups there, and they're aware of the issues.

What happens sometimes is that you become desperate and think, "Well, someone could cut my nerve further or do this kind of block, and all of these things might be effective." I've tended to discourage patients from considering that. If you've been through the different gamut, I also think it's worthwhile sometimes to go back to something you might have taken in the past that didn't work, and retry it. I've had the experience of patients who have said, "Well, I can't use Neurontin. It doesn't work for me; it makes me too sleepy." Then we've retried it at different doses and gone very slowly, and it has helped a little. Or the same thing with

low doses of amitriptyline or nortriptyline, or even using what's called paroxetine – these are three different antidepressants – and having them go back and retry them and see if they offered benefit. Those would be my first-line suggestions.

At the present time, if we look at the centers that are looking most closely at neuropathic pain, the pain clinic at Massachusetts General Hospital might be one, and the group at the University of California at San Francisco, a doctor by the name of Michael Rowbotham. Those are the two places that are looking at nerve pain per se. I don't want to suggest that they have better treatments, and I do think you are in a really good environment. This is my point; this is my continual cry. I'm an advocate for you. We still need better treatments than we have, and we need to figure out a better way to either prevent the syndrome from happening or to help patients who have it. I am enormously sympathetic of what you're experiencing.

CALLER:

Thank you.

OPERATOR:

Thank you. Your next question is from Austin, Texas.

CALLER:

Thank you. I'd like to know if there are any statistics or studies about headache pain during treatment. I developed severe migraines about a week into radiation therapy. I haven't heard you talk about that yet.

KATHLEEN M. FOLEY, MD:

No, in fact, I haven't. The best surveys that have looked at headache in patients with cancer have identified that often migraine comes up as a common cause of headache in a patient with cancer who was previously not diagnosed with migraine in the past. In studies here at Memorial, when someone went back and looked at the causes of headache in a broad population – not just breast cancer patients – migraine did emerge. The question is: Is there something specific about any one of the drugs that you're taking that could precipitate a migraine event?

CALLER:

[Inaudible] You mean the radiation drugs?

KATHLEEN M. FOLEY, MD:

Yeah, I'm going on the chemotherapy side. Those weren't identified.



CALLER:

I had no chemo.

KATHLEEN M. FOLEY, MD:

The question is: Is there something the radiation would do? I think these are two events occurring together in the same person that may not be in any way causally related. But it points out the fact that it's so important for people and for you to know that you have migraine. If this occurred during your radiation, did it occur just once or was it repeatedly occurring?

CALLER:

Repeatedly. It began about a week into it so severe that I couldn't even walk or see or stand. They continued for two or three years, about 20 times a month, until I was finally diagnosed with migraine.

KATHLEEN M. FOLEY, MD:

See, I'm coming back to this – that we've often seen patients who present with headache who had not been previously identified as having migraine. Then the delay that it ...

CALLER:

And I never had.

KATHLEEN M. FOLEY, MD:

Right. No, that's what I'm saying. The point I'm making is that migraine can occur in many different forms in which you might never have had a headache, but you might have other symptoms related to migraine. The point of this is that this is the coincidence of two events, not to necessarily say they're causally related. It becomes so important for you to get the appropriate diagnosis of migraine to be able to get you on a prophylactic treatment to prevent your migraines so that you don't associate it with your radiation therapy.

CALLER:

Okay, thank you.

OPERATOR:

Thank you. Your next question is from Dayton, Ohio.

CALLER:

I had a 7-centimeter tumor removed and undetermined lymph nodes. I should say it was in my axilla. Recently, I have been diagnosed with Horner's syndrome, and I wondered if there is a connection there.

KATHLEEN M. FOLEY, MD:

No, I don't think so. Horner's syndrome is a syndrome where there is a drooping of your eyelid and a smaller pupil on one side. That didn't exist before you had this surgical procedure; is that right?

CALLER:

Not to my knowledge.

KATHLEEN M. FOLEY, MD:

See, sometimes that's very important. It can be helpful to take out old photographs of yourself and show them to the doctor, because it might have been there before, and that would be important. That's number one. The second thing is, I would suggest that you see a neurologist to evaluate you for your Horner's syndrome. My reason for saying that is just to carefully look at your neck and at where – the nerve that mediates the size of your pupil and your drooping of your eyelid runs from your neck down into and above your heart, and that area should be carefully imaged to make sure you don't have anything else going on. It can occur spontaneously, and nothing is ever found. I think that would require a careful assessment, but it's possible you've had it previously.

CALLER:

It happens to be on the same side that I had the ...

KATHLEEN M. FOLEY, MD:

It would be unrelated to your surgery on your breast, and it would be unrelated to your nodes. They wouldn't be near where that nerve is. Okay? They definitely would not be near that nerve. It needs a careful assessment from your neck down into and around the apex of your heart, to just look at that whole area carefully. That's what we would want to have you do.

CALLER:

Thank you so much.

OPERATOR:

Thank you. Your next question is from Las Vegas, Nevada.

CALLER:

I have a couple of quick questions. One is breast pain that comes – it's a couple of years postop from a quadrantectomy/lumpectomy – and it's sharp shooting on and off, and soreness on and off, just intermittently. I don't understand the syndrome of what's going on.

KATHLEEN M. FOLEY, MD:

Did you have that pain before you ever had surgery?

CALLER:

No.

KATHLEEN M. FOLEY, MD:

Never, ever.

CALLER:

No.

KATHLEEN M. FOLEY, MD:

One possibility is that you just have a focal pain in your breast that has occurred spontaneously and has no other meaning. They've done a series of studies where they have looked at women with breast pain to see if it's a predictor of new disease, of breast cancer, etcetera, and it isn't a predictor. Basically, pain in the breast is not a good sign of breast cancer, and the absence is not a sign that it's not cancer. You may be having spontaneous pain related to what is called mastodynia.

CALLER:

I also have scar tissue.

KATHLEEN M. FOLEY, MD:

That's a possibility. I'm raising this other consideration that it could just be spontaneous pain in your chest, and it has nothing to do with scar tissue. However, at the same time, you've had surgery there. You've had some nerves interrupted. It's possible that they fire off at different times, and they possibly fire off depending on your hormonal levels at the time, swelling of your breast, activity, a variety of other causes.

I think there would be two considerations. Easy to say, "It's just a spontaneous pain in the area where you had surgery." That's possible, because the nerves have been damaged in the past. Or, it could be related to changes in your breast tissue itself, unrelated to the surgery. This is what's been reported in the literature. I don't have a huge experience of seeing women who don't have cancer to assess their degree of breast pain, but it's commonly reported and may be hormonally related and structurally related to your breast and unrelated to any history of cancer or cancer.

CALLER:

Maybe because I have fibromyalgia – I don't know if that would make a difference.



KATHLEEN M. FOLEY, MD:

That could play a role in it, because you might have a heightened sensitivity to nerve injury-type pain. That may be playing a role. The good news is that it's not related to cancer usually.

CALLER:

Why is the pain mostly in hands and feet from the aromatase inhibitors, nowhere else? It's typically the stiffness, the morning stiffness. Once I get going – and I think this is typical for many people – and moving, it dissipates. But if I lie down or sit down for a little while and get up, it starts again. Why is it mostly the hands and the feet where it's contained?

KATHLEEN M. FOLEY, MD:

No one knows the answer to that, and I think in some patients it's not contained. It's just the hands and the feet. It's a diffuse joint problem. But I think no one knows that answer.

CALLER:

Are they doing anything with Lyrica?

KATHLEEN M. FOLEY, MD:

Lyrica is the second drug after gabapentin. Its generic name is pregabalin. When someone has not been effectively treated with Neurontin, there is often a trial of pregabalin, or Lyrica. Both drugs, both gabapentin and Lyrica, work 50 percent of the time in 50 percent of patients with nerve injury pain. It's being tried, but it has not been tried in those patients with joint pain from the AIs in any kind of major study.

CALLER:

Oh, okay. That's what I wanted to know, because Neurontin made me dizzy and unsteady and falling and walking into walls.

ELYSE S. CAPLAN, MA:

Thanks so much, and keep talking with your doctor about your concerns so you can get the most effective treatment.

CALLER:

Thank you so much.

OPERATOR:

Thank you. Your next question is from Philadelphia, Pennsylvania.

CALLER:

Hi. I'm calling to talk about radiation therapy. I'm seven years post a lumpectomy, node dissection, radiation therapy. In the midst of the radiation therapy, I had problems with range of motion with my arm. It sounds to me like I have

that syndrome with the chest also, and I have lymphedema. My question is how radiation therapy – because I heard you say several times that chemotherapy can initiate some of these symptoms – affects a relationship to neuropathy?

KATHLEEN M. FOLEY, MD:

Again, we haven't seen any examples where radiation therapy can produce or make a neuropathy worse. Looking at patients who have had what we've been calling nerve injuries on the breast wall, this postmastectomy syndrome, we have not seen radiation therapy make that worse. We have looked at a large number of patients. But difficulties with range of motion occur in upwards of about 20 percent of women following their surgery who then have radiation therapy. This is very, very common, and it points, I think, to a critically important part of why physical therapy and full mobility of the joint is so, so important.

Often times what happens is, after the surgery, you have pain in your chest wall or pain in the axilla, so you start protecting that arm and reducing it and can develop what's called a frozen shoulder. So, again, early on we want people moving their arms as best as possible and getting the best pain control they can have. But even now, if you have limitation in your range of motion, it would be really helpful for you to be seen by a physical therapist or physiatrist to get that arm as exercised as possible. It shouldn't make your pain any worse, but you want to keep that range of motion fully active and not let the shoulder get frozen in place.

CALLER:

Just another thing: I've been really having problems with reinjury, like you just talked about. They did put me on Neurontin, which I also had problems with. I was falling and I was dizzy. Now I've tried several different meds, and I'm on an antidepressant med at this time. It does take away the edge of that pain. It doesn't take it away completely.

KATHLEEN M. FOLEY, MD:

But it does reduce it.

CALLER:

But for those who were concerned about taking an antidepressant drug, it really did help to take the edge off.

KATHLEEN M. FOLEY, MD:

In my own experience in treating patients, we have found with the use of a drug like amitriptyline or nortriptyline that they're very specific. They're

known to be analgesic [for] neuropathic pain. They can be really helpful. It doesn't mean you have to stay on them forever. It's helping you through a period of acute or exacerbated pain and helping you to be able to do the physical therapy. That's very helpful for you to report that it was helpful to you, because that's been my experience, hearing what patients have reported. I've had much better success with that than even with Lyrica.

ELYSE S. CAPLAN, MA:

Thank you. With that, I'd like to sincerely thank Dr. Foley, on behalf of Living Beyond Breast Cancer, for her time and her expertise. I want to thank all of the participants who were listening and those who asked excellent questions. We hope some of what you learned today will positively affect your quality of life every day and at least equip you with information to go back to your oncologist and other health providers to try to get your pain under better control.

Again, to Dr. Foley's point about not only getting the right health providers and communicating with them about your concerns, but also talking with other women about what might be helpful to them: Living Beyond Breast Cancer's Helpline at (888) 753-5222 is one way to connect with peers for support, and our message boards at <http://lbcc.org/> have ways to post messages and get some of your concerns heard. With that, if Dr. Foley has any closing comment, we'd love to hear that now.

KATHLEEN M. FOLEY, MD:

I think it's very hard to live with pain and to live with the persistence of pain, so the best way we can help you is to say that we're searching, as you're searching, for the best treatment, for the most effective treatments for you, and it can be difficult. I continually am optimistic, though, because I've seen people be better when I didn't think they were going to be better. I've seen different drugs work when we've retried them. I've also seen this extraordinary ability of people to try to live with their pain, as difficult as it is. I'm sorry you have to live with these difficult situations, but those of us who are trying to work on this are working hard to try to make it better. Hopefully we can. I'm very optimistic that we can make this better.

ELYSE S. CAPLAN, MA:

Thank you so much, Dr. Foley. All of the participants, we hope you have a good rest of your day and that you'll stay in touch.

[END OF TRANSCRIPT]