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CURE MAGAZINE FACEBOOK CHAT: NEUROPATHY AFTER CANCER

July 9, 2014

Transcript Highlights from the Facebook Chat

On July 9, CURE hosted a Facebook Chat on neuropathy after a cancer diagnosis. We invited **Pam Shlemon, Executive Director of the Foundation for Peripheral Neuropathy (FPN), Michael Stubblefield, MD who is a cancer rehabilitation physician at Memorial Sloan Kettering Cancer Center;; and CURE's editor-at-large Kathy LaTour** to answer your questions on neuropathy. Stubblefield specializes in the identification, evaluation and treatment of neuromuscular, musculoskeletal, pain and functional disorders caused by cancer and cancer treatment. In addition to neuropathy, he also takes care of complications of radiation and surgery as well as of the cancer itself.

This was one of the most fast-paced and involved chats we've had to date. Our experts answered most of the questions posed during the chat and a few that were emailed and posted ahead of the chat on the Events page.

Here is a selection of the questions answered during the chat:
Q: CURE magazine-*Our first question for our panel comes from an earlier email: Pam, what are the main symptoms of neuropathy? Can there be different symptoms for different people?*
A: Pam Shlemon, FPN- CIPN symptoms usually appear symmetrically in a stocking-glove shaped distribution in the feet and hands. Typical symptoms include numbness, tingling, burning and electric-shock like symptoms or muscle weakness. Affected patients can experience impairments including difficulty in walking, increased risk of falls and weakness and restrictions in fine motor skills such as writing and other manual tasks buttoning your shirt.
Q: Kris-*Today is Round 12 of 12...The neuropathy (both fingers and feet) didn't come on until the last week or two...Should it go away over time? Is there any kind of exercise/therapy I can do to help get rid of it?*
A: Kathy LaTour, CURE-This is one of those questions that is answered with a probably. Doctors don't know who will get neuropathy and they don't know when it will end. The majority of neuropathy resolves over time after treatment ends. I have friends whose neuropathy resolved over a year and some over six months.
Q: Janet*-I had breast cancer over 11 years ago and one of the chemo drugs I was on was taxatear...I started having neuropathy in my feet, toes, and fingers then. I still have some problems with it today. Does neuropathy still happen years after treatment?*
A: Dr. Michael Stubblefield -One of the common questions I see asked is if the neuropathy will ever go away. The answer to this depends... Most of the time chemotherapy-induced neuropathy does improve over time. In some cases, however, it never goes away. That being

said, there are usually effective medications to treat the pain and tingling that goes along with neuropathy. Weakness can usually be improved with physical therapy. Numbness (the lack of sensation) and other symptoms don't respond to medication. The most common causes of neuropathy in the cancer setting are chemotherapy and the cancer itself. There are a number of less common causes like paraneoplastic disorders. Paraneoplastic disorders occur when the tumor secretes a hormone or protein that causes problems. For instance, certain types of lung cancer (Small Cell) are known to cause a paraneoplastic peripheral neuropathy by causing the development of an antibody that damages nerves. Nerve damaging chemotherapies include the taxanes (taxol, paclitaxel), the Vinca alkaloids (vincristine) and the platinum drugs (carboplatin, Cisplatin). Other types of chemotherapy such as thalidomide, Bortezomib, Epothilones also cause neuropathy. The type of neuropathy caused by the platinum drugs and most other types of chemotherapy can be very different because of the way they affect the nerves. Taxanes and Vinca alkaloids damage the long axon fiber of the nerve and tend to cause a neuropathy that can be painful, or associated with abnormal sensations (paresthesia). Weakness is also a common feature of these medications in severe cases. The platinum drugs damage the cell body of the nerve as opposed to the axon and tend to cause more sensory issues such as pain and sensory loss. Platinum drugs do not usually cause weakness although they can cause problems walking because the sensation nerves are greatly affected. It is important to determine what the exact cause of symptoms is because the treatment can be very different. For instance, if a patient has tingling in the hands because of carpal tunnel syndrome they might benefit from occupational therapy, hand splints, anti-inflammatory medications, or even surgery.

Q: Bill-*Is there a difference between neuropathy from diabetes and from chemo? How about Parkinson's?*

A: Pam Shlemon, FPN-Just the only difference is the causes, the symptoms are typically the same and the treatments are also typically the same. The only difference is the nerves that are affected - small fiber and/or large fiber

Q: Robin*-Will acupuncture help?*

A: Pam Shlemon, FPN- Not every treatment works for all patients. Patients that I have spoken to who have tried acupuncture are mixed. Some patients have found relief and others have not. Treatments for PN are not a "one-size" fits all. It is worth giving it a try - there is something out there for everyone.

Q: Bill-*Can radiation cause neuropathy?*

A: Michael Stubblefield-There is a question about if radiation can cause neuropathy. This is one of my favorite topics. Radiation does NOT cause peripheral neuropathy but it can damage the nerves running through the radiation field. For instance if a patient received radiation for breast cancer years ago they can develop brachial plexopathy which will cause numbness, tingling, weakness, and other symptoms that mimic neuropathy. Similarly, focal radiation for things like sarcoma can damage the nerves that go through the field. This is called a mono (meaning one) neuropathy as opposed to a polyneuropathy.

Q: CURE magazine-*I had SGAP (breast reconstruction surgery) five years ago. I have tingling and numbness above, below and to the sides of the incision. I had no idea that this could happen. How many others have neuropathy from surgery alone? Is there anything that helps?*

A: Dr. Michael Stubblefield -There is a question on pain in the breasts or armpit after mastectomy and reconstruction. This is a situation where neuropathic symptoms are NOT caused by peripheral neuropathy. It sounds like you have what I call post-mastectomy reconstruction syndrome (aka, post-mastectomy syndrome). Numbness, tingling, spasms, arm weakness, a feeling of constriction in the chest and a number of other symptoms often result from mastectomy and importantly reconstruction. There are a number of different disorders

that make up this syndrome but none are peripheral neuropathy. In this case, it sounds like the small nerves that supply the chest and sometimes back were damaged during the surgery and reconstruction. A number of other issues like restriction of the fascia (connective tissue that binds the muscles and bones) are also contributing. This is not uncommon. One nerve that is often damaged is called the intercostobrachial nerve. It is important to understand that this isn't a surgical complication per se but simply a consequence of the surgery that happens in a small percentage of women. The treatment varies but physical therapy emphasizing myofascial release is often extremely helpful. Some of the same medications used to treat neuropathy such as duloxetine (Cymbalta), pregabalin (Lyrica), or gabapentin (Neurontin) are also often very useful. One of the common questions I see asked is if the neuropathy will ever go away. The answer to this depends... Most of the time chemotherapy-induced neuropathy does improve over time. In some cases, however, it never goes away. That being said, there are usually effective medications to treat the pain and tingling that goes along with neuropathy. Weakness can usually be improved with physical therapy. Numbness (the lack of sensation) and other symptoms don't respond to medication. There are questions about the percentage of patient who get neuropathy from chemotherapy. The answer is that it depends on the type of chemotherapy, the dose, and the way it was delivered as well as the type of patients who get it. While 40% may get neuropathy with certain medications and regimens, it goes away for many of them. Unfortunately, not everyone will have the neuropathy go away.

Q: CURE magazine-*What types of integrative therapies are worth trying for patients with neuropathy?*

A: Pam Shlemon, FPN Complementary: While complementary and alternative forms of medicine are often thought of interchangeably, there are differences. Complementary therapies are used together with conventional medicine. This might include a regimen of vitamins, supplements, herbs, and 'natural' substances to be used in conjunction with other medications. Integrative: A total approach to health care, integrative medicine combines conventional and CAM therapies into a treatment plan where there is some high-quality evidence of safety and effectiveness. Complementary and alternative medicines (CAM) are divided into several broad categories

> **Natural Products:** This category is the most popular form of CAM, used by more than 15% of the U.S. population. These include herbal medicines, vitamins, minerals, and products sold over the counter as dietary supplements.
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> **Mind and Body Medicine:** Using mind and body practices that focus on the interactions among the brain, mind, body, and behavior, to affect physical functioning and promote health. Examples are: Meditation, yoga, acupuncture, deep breathing exercises, hypnotherapy, progressive relaxation, and tai chi.
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> **Manipulative and Body-based Practices:** These practices focus primarily of the structures and systems of the body, including bones and joints, soft tissue, and circulatory and lymphatic systems. Spinal manipulation and massage fall into this category
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> **Energy medicine:** This practice is among the most controversial of the CAM therapies. These therapies involve the manipulation of various energy fields to affect health. The most common practices include those involving electromagnetic fields (magnet and light therapy).
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> **Q:** I have RFS and some neuropathy after having HD in 1989. *I live in Ireland and was wondering if there are any of your colleagues working in this part of the world.*

A: Dr. Michael Stubblefield-Unfortunately there are not a lot of doctors who have knowledge and experience with this disorder. While we are training a number of Cancer Rehabilitation

Fellows here in the United States, I don't know of physicians in other countries who would be able to deal with the neuromuscular and musculoskeletal complications of HL. Treatment of these conditions requires a team approach from both physicians and therapists. There are doctors who have knowledge of the cardiac, secondary cancer, and other medical effects. These are usually in Survivorship Programs.

Q: *Can you reduce your risk?*

A: Pam Shlemon, FPN-Collaborate with your team and report symptoms you notice during treatment: Dose reduction, rest period, or halt therapy may all help in reducing your risks.