



PATHWAYS

A Study of Breast Cancer Survivorship

A NEWSLETTER FOR STUDY PARTICIPANTS

SUMMER 2020

NEUROPATHY: BREAST CANCER-RELATED NERVE PROBLEMS

Many people who have had breast cancer experience pain or discomfort caused by damage to the nerves, known as neuropathy. Nerves control our sense of touch, how we feel pain and temperature, and our muscle strength, so these changes can impact our quality of life after cancer. This is a condition that researchers still have much to learn about.

Neuropathy is different for each person. It depends on which nerves and how many are damaged. It can start during cancer treatment or shortly afterward. Nerve problems may end, or they might get worse after treatment ends. Often patients only hear about the acute side effects and may not know that neuropathy can result from cancer or cancer treatment.

Neuropathy symptoms can include:

- Numbness, tightness, and tingling
- Burning, shooting, or stabbing pain
- Weakness and loss of balance
- A change in sensitivity to touch or temperature—either feeling more (extra sensitive) or less (loss of feeling)

Paula is a Pathways participant who never had pain or neuropathy; she “always wondered why they asked me about pain when I went in for my visits.” Another cohort member said that her fingers and toes were tingly and sometimes painful, but “not so much that I couldn’t continue on with my normal routine.” Sue and Linda, however, have fairly severe nerve problems that have lasted for years. They shared their stories with Paula.



Most often neuropathy affects the hands, arms, feet and legs. For both Sue and Linda, feet are most affected and it is worse at night. For Sue, on the nights when it flares up, it is difficult to sleep. “I can’t stand anything on my feet,” she said. “It’s strange that although I can’t feel my feet, I can feel the pain.” Linda’s heels throb at night and she sleeps on her side to avoid having them touch the mattress. When she wakes up, she must sit on the side of the bed and wait before she can get up.

For Linda, the numbness and dull aching pain has gotten worse over time. “I’m limited as to what I can do,” she said of the neuropathy. Sue experienced a loss of balance because “I had no feeling in my feet, so I started using a cane.” She also had an electrical shock feeling in her feet and hands, then it would go into her legs and arms. Because of the neuropathy, she can’t drive or ski now. “It was tougher giving up things I can no longer do than it was finding out I had cancer,” Sue told Paula.



Continued inside

Neuropathy: breast cancer-related nerve problems *continued*

Causes

Chemotherapy is the most common reason for neuropathy in people with breast cancer, particularly taxanes



(e.g. docetaxel, paclitaxel) and platinum (e.g., cisplatin, carboplatin). Health care providers balance medication combinations, dosing, frequency and duration to reduce the risk of recurrence and to maintain the best possible quality of life. Newer immuno-therapies can also cause neuropathy.

Neuropathy can start any time after treatment begins, and it may worsen as treatment continues. Sue's symptoms began with her second taxane treatment. With each treatment, problems with her balance, burning pain, and tingling (like pins and needles) increased. Linda's neuropathy began in the middle of her chemotherapy treatments, first with numbness in her hands, then in her feet.



Surgery and radiation therapy also may cause damage to nerves in the chest and underarm areas, which can lead to

neuropathy in those areas. Advanced breast cancer itself can damage nerves. Sue has nerve pain where tissue was removed from her mastectomy. While it has improved with time, she can't wear a bra or prosthesis because of the pain in her chest, and there are times she feels embarrassed because "I don't look the way I would like." Linda didn't experience pain

at the surgical site after the mastectomy, but she has numbness and tingling where the nipple was and an occasional sharp twinge of pain.

Two other participants told us that their neuropathy started after radiation therapy. Sandi said that little sharp electrical shock feelings would come and go over the course of radiation. Maria had similar problems with her nervous system during radiation and they got worse after. She still has sporadic tingling and burning sensations in her feet when sitting and after walking, and her "feet, arms, (and) hands also get icy cold."

Who gets Neuropathy?

An estimated 15-23% of breast cancer patients who receive taxanes experience neuropathy, and symptoms last more than a year in about two-thirds of patients. Our Pathways researchers are continuing to investigate who is most likely to have more severe and longer-lasting nerve problems and what works best to treat them.

So far we know that neuropathy that lasts for two years after treatment is more likely in older patients, those who had a mastectomy, are overweight or obese, had more lymph nodes containing cancer cells, or already had neuropathy or a related condition like diabetes. Our genes also play a part: Sue's younger sister has neuropathy of unknown cause and her doctor said that put her at higher risk.



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Treatment for Neuropathy

Nerve problems can be addressed in several ways and what works varies by person.

- A range of **medications** are used to treat neuropathy, from over the counter or prescription pills for inflammation and pain, antidepressants, and topical creams or patches to put on the affected area(s).
- **Physical therapy programs or exercises programs** designed for people with neuropathic pain and balance problems can help.
- Transcutaneous electrical nerve stimulation (**TENS**) is effective for some people.
- **Complementary medicine techniques** such as **acupuncture** and **massage** can stimulate and restore feeling in our nerves.
- **Deep breathing** and **mindfulness** practices can help some people with neuropathy and related sleep problems.

Sue's care team tried different medications to find the combination that works for her. She had taken them for so long, she wondered if they were still effective. "I found out when I was in the hospital and did not take them for a week—they do make a difference!"

Linda found that painkillers didn't help her. Maria says that both yoga and Feldenkrais exercises made her feel better.

Sue found that she could modify her old activities. For her, a step-through bike gave her a better sense of control than walking. She isn't comfortable riding on streets and can't go as far as she used to on a mountain bike, still she says, "It makes me feel alive! To get out and do this is wonderful."

In the beginning, Sue said she would put her feet "in a tub of iced cold water to help relieve some of the pain." While massage brings relief to some, being touched was too painful for her. She tried acupuncture which helped, but she did not go back often enough "to see long-range improvement."

And, of course, a healthy, balanced diet helps with neuropathy. Alcohol and tobacco smoking/vaping can make neuropathy worse, so it is best to avoid them.



We each must find what works for us. Some general resources are listed below. If you have nerve problems, **talk to your health care provider** about your symptoms, especially if they are severe or affect your daily life.

Coping with nerve problems

Keeping safe is critical for people with neuropathy.



Lack of feeling increases the risk for burns in bathing, cleaning and cooking. It can help to wear shoes or slippers, to



protect our feet. Researchers have found that people with neuropathy have a greater risk for bad falls. There are more tips on the Health and Wellness section

of the KP website; search for "neuropathy from chemotherapy" or "neuropathy."

For Linda, it is hard to predict when the pain or numbness will hit her. "I have to be careful how far I walk or how long I stand." Linda reported that, while it doesn't take the pain away, "I meditate every day for stress and relaxation and keep my mind focused on good things." Spiritual readings and sitting or walking in nature help Maria with her pain.

In the beginning, Sue had trouble with many daily tasks, and walking, even with a cane, was difficult. Now she is doing better and rarely uses a cane. "I've learned to cope with the help of the medications; it's been 7 years. It is still more painful at night. I do things that need to be done in the morning and take it easy in the later afternoon."

Having help can also be critical. Sue's sister and a friend who is a nurse have been great resources for her. "It takes a lot of people to get your life back on track as best that you can."

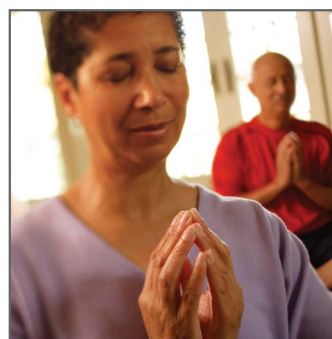


Resources for People with Neuropathy

In addition to the information on the Health and Wellness section of the KP website, Kaiser Permanente offers a variety of classes that promote healthy lifestyles and can benefit those of us with neuropathy or other chronic pain. Some examples are listed below. At this time, to help prevent the spread of Coronavirus/COVID-19, all in-person classes have been cancelled, but many are meeting online. Contact your Health Education Department to see what resources are available for your needs.



Mindfulness-Based Stress Reduction



Get back in your body and gain perspective by practicing mindfulness meditation and gentle movement. These methods can help you manage stress, chronic pain, illness, anxiety, and depression.

Qi Gong for Beginners

Enhance your everyday life and health by learning to develop energy (qi) and balance your mind, body and spirit. Qi Gong can help you improve strength, flexibility, and balance, which can help prevent falls as well as help reduce your stress, pain, and symptoms of chronic ailments.



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Tai Chi

The Chinese practice of Tai Chi combines steady, flowing movements and deep breathing to promote flexibility, circulation,

and balance. It may also help reduce stress, pain, and other symptoms of ongoing conditions.

Feldenkrais Method

The Feldenkrais Method® seeks to affect change by working with your nervous system. The method helps reorganize connections between the brain and body and thus improve body movement and psychological state.

The Pathways Study and COVID-19

The Pathways Study staff is following the public health guidelines established to prevent the spread of COVID-19, but much of our work continues. In early March, we submitted a grant application to continue the Pathways Study for five more years and support the study into 2026.

Regarding the coronavirus, breast cancer survivors generally do not need to have any greater concern than the general population. Although some cancer therapies may result in decreased immunity during treatment, most Pathways Study participants are many years after diagnosis and treatment. If you are undergoing active treatment and have health-related questions, please contact your treating physician.



We are continuing to contact our participants to complete our surveys. The 96-month follow-up survey is a very short questionnaire that you can complete in about 5 minutes. Those of you who have completed the 96-month follow-up questionnaire are now being contacted to complete our annual follow-up survey, this questionnaire takes on average about 15 minutes to complete. We try to accommodate everyone's schedule; we hope you can find a little time to complete these surveys. In order to learn more about neuropathy and other aspects of breast cancer, it is critical to have as many participants as possible complete each survey.

Our next newsletter article will cover heart health issues as a side effect of breast cancer treatment. Do you have an idea or a story to share about how your cancer or treatment caused heart health problems that continue at least 2 years later? Please send a brief summary via email to **DOR-pathways@kp.org** and we may contact you for an interview this fall of 2020. Thank you!



As always, we greatly appreciate your continued dedication to the Pathways Study. If you missed our call and would like to complete your survey, you can reach us at our toll-free number **1-866-206-2979** or email us: **DOR-pathways@kp.org** ☒

For the most up to date information on the Pathways study, please visit our website:
<http://pathways.kaiser.org> ☒

New Contact Information?

In order to keep in touch with you we must have your latest contact information. Please let us know if your phone number, home address or email address has changed. You can reach us by calling our toll-free number: **1-866-206-2979** or email us: **DOR-pathways@kp.org** ☒



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